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Family and staff perspectives on quality of life, well-being and human rights for people with advanced dementia living in care homes: a case study approach

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Family and staff perspectives on quality of life, well-being and human rights for people with advanced dementia living in care homes: a case study approach

Sian Ellen Hughes

Declaration

I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.

I confirm that I am submitting the work with the agreement of my Supervisors.

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I Mam a Meical, er cof am Dad

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Abstract

This thesis explores the quality of life (QoL), well-being and human rights of care home residents living with advanced dementia. Increasing attention is being rightly paid to well-being and rights of people living with mild to moderate dementia, but we understand much less about how to identify and support their maintenance and improvement in those living with advanced dementia. Ensuring personalised and individualised care where the person has limited or reduced capacity remains a major challenge, but essential in maintaining the person's rights and ensuring their choices remain at the forefront of care.

The thesis presents a systematic review of suitable QoL measures in advanced dementia, and two empirical studies, in a total of four care homes providing care for people with advanced dementia. The thesis adopts a mixed method approach, largely qualitative but supported by quantitative measures, and including observation of individuals living with advanced dementia. The first empirical study comprises interviews with staff and families, observations of residents and ratings of quality of life given by family members and care staff from two care homes within the same organisation. Results from an inductive thematic analysis of interviews with family and staff demonstrated the importance of family involvement in care of residents living with advanced dementia and the lack of discussion around human rights, coupled with confusion and a negative perception of human rights in care homes. Two in-depth case studies explored the daily lived experiences of residents living with advanced dementia in the context of relatives' and staff members' perspectives. Data presented from both case studies highlighted experiences of two unique individuals, living with the same condition, who show remarkably different ways of expressing happiness, affection, humour and distress. The case studies demonstrate that, even with limited verbal communication abilities, the person remains an individual, and with the support of others, can experience QoL and well-being.

For Study 2 two additional care homes were recruited, to extend the breadth and scope of Study 1 findings on quality of life and well-being and, particularly, human rights in advanced dementia. A care home operated by a different organisation was included, as well as a home undergoing major change in management and environment and in the period of transition. The aim was to explore the experiences of families and care staff in more detail, with interviews supported by questionnaires. An instrumental collective case study approach was taken, with the two care homes presented as individual cases, with relatives and care staff perspectives embedded in each.

The qualitative data resonated strongly with the themes of Study 1, and therefore, a further analysis of the data was undertaken. Applying a relationship lens produced a set of themes representing the key relationships and their implications for well-being. The data highlighted the importance of the well-established 'Triangle of Care', demonstrating the importance of relationships between residents, relatives, and care staff and how their well-being is influenced by the quality of these relationships. The further exploration of human rights demonstrated the complexities and challenges faced by families and care staff regarding issues such as autonomy, individuality, dignity, best interests, decision-making, and the importance of activities for individuals living with advanced dementia. Family involvement in the care homes supported the residents' human rights, and the care home culture – especially time pressures - influenced many aspects of how the residents' rights were upheld in practice. The contrasting care home environments and cultures illustrated how different environments/cultures can either promote relationships and support rights to be upheld or can cause tensions in the relationships in the home, contributing to ill-being of residents, relatives and care staff, with significant implications for maintaining human rights.

Further research is suggested to expand the findings across a broader range of care settings and to consider further the situation of residents who do not benefit from regular and frequent visits from family or friends. The potential for human rights approaches to be incorporated in training and development initiatives in care homes, so that they may be embedded in day-to-day care practices, should also be evaluated.

Chapter 1: Introduction

Dementia

Prevalence and impact of dementia

In the UK in 2019 there were an estimated 850,000 older people with dementia (Alzheimer's Society, 2019), representing 1 in every 14 of the population 65 years and over. Ageing is a worldwide process, and over the past century, the world has seen unprecedented decline in mortality, which highlights the successes of improved health care, resulting in the increase in population. Many older people are now living longer and healthier lives and so the world population has a greater proportion of older people (Tom, Hubbard & Crane, 2015). Given the increased prevalence of the condition with age, coupled with an ageing population and longer life expectancy, the number of people affected by dementia continues to grow.

There are numerous different types of dementias, with Alzheimer's Disease being the most common form, accounting for two thirds of all cases, around 500,000 in the UK (Alzheimer's Research UK, 2018). The second most common form is vascular dementia, accounting for 20% of cases, followed by Lewy Body Dementia (15%). Dementia is typically said to progress in three stages, 'mild', 'moderate' and 'advanced', referring to the progression of the illness (Alzheimer's Research UK, 2018). Dementia is characterized by prolonged and progressive disability, complicated by aging-related care needs and a high rate of comorbidity, making it difficult to identify the terminal phase of the disease (Brown et al., 2013). However, people may not progress into the later stages of the illness, due to other health conditions and older age when the symptoms were first experienced.

The later stages of dementia are usually referred to 'advanced' or 'severe' dementia but giving a clear definition has not been straightforward. The term 'advanced dementia' is often linked with death and dying, and therefore, attention has focused on end of life care. However, the symptoms in advanced dementia are complex and although the term is widely used, there is a lack of definition in practice, policy and research literature (Hanson et al., 2017). The following definition of advanced dementia was developed from the European Palliative Project (Tolson et al., 2016) through the involvement of professional health care practitioners and family carers:

"Advanced dementia is associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks. Addressing advanced dementia related health needs requires expert health care, nursing and palliative care assessments together with insights provided by family carers and others, particularly when the person has difficulty

communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying. The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography and socio-economics." (McLeish, 2019, pp.14-15).

The economic impact of dementia on society is large, greater than cancer and heart disease combined (Care Policy Evaluation Centre, 2019) with figures showing the total cost of care for people with dementia in the UK alone is £34.7billion, which is predicted to rise significantly, by 172%, over the next two decades, to £94.1billion in 2040. These figures include all those associated with supporting older people 65 and above with dementia, rather than the additional costs attributable specifically to dementia itself.

Currently there are no disease modifying treatments available for dementia. In recent years, the emphasis on early detection and treatment has been developed further to include the potential for prevention, or of delaying the onset, of dementia. A growing body of evidence exists which supports modifiable risk factors, prevention and intervention methods, including physical activity, avoiding smoking and excess alcohol consumption, eating well and engaging in activities all promoting overall health and well-being. Additionally, risk factors for heart disease such as hypertension, obesity and diabetes seem to increase the risk of dementia and provide targets for preventative efforts (Livingston et al., 2020).

A small number of medications are available at present for Alzheimer's disease specifically, which are associated with benefits to cognitive and behavioural outcomes, but their clinical impact remains modest (Preuss et al., 2016). They are mainly intended to be prescribed in the mild / moderate stages of the condition. However, increasing evidence exists to suggest the benefits of non-pharmacological treatment (NPT; Olazarán et al., 2010). NPT is non-invasive and may improve independence, and quality of life (QoL; Olazarán et al., 2010). NPT involves a wide range of interventions, with the aim of improving symptoms and QoL, based on different methodologies, ranging from simpler environmental interventions and reminiscence to more complex approaches involving virtual environments (Olazarán et al., 2010; Zucchella, et al., 2018). Again, they have mainly been used and evaluated with people in the mild / moderate stages of dementia. People living with advanced dementia have been neglected in terms of these interventions, with multi-sensory approaches, such as Namaste and Snoezelen the major exceptions (Bunn et al., 2018). Interventions such as Namaste Care have focused on enhancing QoL for individuals living with advanced dementia, creating a multi-sensory environment and stimulation, to reflect the personalised preferences of the individuals (Banerjee & Ford, 2018). The focus is to create a calm and soothing environment, where interactions are unhurried and focused on the loving touch approach (Stacpoole et al., 2016). Evidence suggests Namaste Care increases social interaction and reduces the severity of behavioural symptoms, such as agitation, and improves families' satisfaction with care (Simard & Volicer, 2010). The Namaste Care Programme does not require a specific room (Stacpoole et al., 2016) however, it is recommended that a Namaste space is created to facilitate the sessions. Specific multi-sensory rooms that exist in care homes are typically known as 'Snoezelen' rooms. The Snoezelen room is designed to offer stimulation to multiple senses. Snoezelen has become an increasingly popular approach in dementia care (Bauer et al., 2015), with the aim of enhancing well-being for people living with dementia (PLWD) and their families and care staff (Jakob & Collier, 2017). Snoezelen provides a multisensory environment that can both stimulate and relax the individual, which can be tailored to suit individual preferences. The application of Snoezelen in dementia care has focused on creating a rich environment to stimulate the primary senses of sight, smell, hearing, taste and touch (Bauer et al., 2015).

Care home placement and advanced dementia

Due to the increased prevalence of the condition with age and longer life expectancy, according to estimated projections (CPEC: Wittenberg et al., 2019) the number of individuals living with advanced dementia is expected to double, with social care costs projected to triple, by 2040. Current figures indicate that seventy percent of people with advanced dementia live and die in care home placement (Wittenberg et al., 2019). With figures suggesting that in the future a higher proportion of people will be living with advanced dementia, and with the likelihood of requiring social care increasing with dementia severity, it is essential to plan care effectively and understand the level of care that is required (Wittenberg et al., 2019).

Historically in the UK, care for people with advanced dementia, if not provided at home by families, was provided by the NHS in psychiatric hospitals (often in the former 'asylums' from the Victorian era), and geriatric hospitals (often in former 'workhouse' buildings), which would have a number of 'long-stay' wards, providing care until the person died. Over time, responsibility for the management of advanced dementia began to shift from the NHS to 'social care', to be replaced by largely private sector provision of home care services and a mix of for-profit and non-profit private provision of nursing home care (Peace, 2003) where funding from the local authority (responsible for 'social care') would be subject to means-tested charges. Despite the apparent availability of

NHS Continuing Health Care funds to fund the 'health' component of care, research from the Alzheimer's Society found that these funds are often not accessible for people living with dementia. People living with dementia face higher care costs, in some instances up to 40% more than the 'standard' price by the same provider, and the number of local authorities offering increased rates to providers for dementia care has continued to decrease. This has led to increased demands for relatives to pay 'top-up fees', and increased the risk of poor quality care, as providers are underfunded and operate on a shoestring budget (Alzheimer's Society, 2018).

Dementia as a terminal condition

Advanced dementia has largely been unrecognised as a terminal illness (Mitchell et al., 2009). The duration of dementia may range between two and 15 years, with individuals living in advanced stages for as long as three years (Shuster, 2000). Where individuals are living with a condition such as cancer, specialists have knowledge about the progression and trajectory, making it possible to identify when the person is dying (Dening et al., 2012). Previous research has identified that healthcare workers had difficulty identifying when a person living with dementia was at the end of life (Dening et al., 2012; Sachs et al., 2004). Additionally, whilst dementia is accepted as progressive, individuals may have difficulty accepting the illness as a cause of death. A person may die from another condition at any stage of living with dementia, but especially so in advanced dementia, where individuals are vulnerable to developing apraxia, dysphagia, and increased vulnerability to infection, malnutrition, and other adverse outcomes (Dening et al., 2012). Although dementia may be considered, it is likely to be recognised alongside another health condition, as opposed to being cited as the cause of death, with studies of death certificates indicating dementia may be overlooked as a cause of or contributor to death (Sachs et al., 2004).

Dementia and interaction with comorbidities

A review conducted by Bunn and colleagues (2014) found significant numbers of PLWD are also living with a comorbid health condition, such as diabetes or hypertension. However, the findings suggest PLWD did not receive access to services to support the management of these comorbid conditions to the same extent as those with similar comorbidities without dementia. The review suggests this may be due to the likelihood of PLWD being unable to report their symptoms and being reliant on others to monitor and arrange access to services. Further it was suggested, this may be because the so-called behavioural and psychological symptoms of dementia may become clinically dominant with the comorbid conditions being overlooked and unseen (Bunn et al., 2014; Kerr et al., 2007). A recent study by Collinson and colleagues (2019) identified in the UK alone an estimated one in thirteen (7.5%) people aged 75+ with a cancer diagnosis also have a dementia diagnosis. Whilst comorbidity is well recognised within cancer care planning and decision making in older people, few studies have given focus to dementia as a comorbidity (Surr et al., 2020). A recent study by Surr and colleagues (2020) identified that dementia alongside cancer requires significant care planning and support, more than managing multimorbidity alongside cancer generally. The study focused on outpatient services and found PLWD were faced with many challenges navigating appointments, which included the travel to the oncology unit for many. Further, the study identified family members were crucial in navigating care and, without this support, people with dementia may fall between the gaps (Surr et al., 2020).

End of life care provision and dementia

Despite national dementia strategies encompassing the entire dementia journey from early detection to the end of life, they may not link with palliative care planning and support; historically palliative care has been the focus at the end of life for individuals with cancer. Palliative care has been defined as a crucial part of integrated person-centred services (World Health Organisation, 2020) optimising QoL and providing comfort to individuals and their families, including physical, emotional and spiritual care (NHS, 2015). Despite complex needs, people with advanced dementia often receive fragmented and suboptimal care at the end of life (Kupeli et al., 2018).

A review of palliative care in national dementia strategies across 14 countries (including the UK) cross-examined the strategies against the European Association for Palliative Care Guidelines (EAPC; Van der Steen et al., 2014). The strategies across all countries cover most of the domains and recommendations set by the EAPC. However, most frequently there is no explicit mention of their procedures as palliative care. The review identified common areas: person centred care, communication, shared decision making, continuity of care and family involvement (Van der Steen et al., 2014). Although these areas are important, they are important throughout the dementia journey, and are not exclusive to dementia care or palliative care. Additionally, the national strategies cover the medical issues in palliative care, such as avoiding ‘aggressive, burdensome or futile treatment’ and ‘optimal treatment of symptoms providing comfort’, to a lesser extent than the EAPC. Despite this, all the strategies lacked reference to timely recognition of the person approaching death. Given the increase of people living with and dying with dementia, it has been recommended that end of life care planning, should be embedded as part of the national strategies (Nakanishi et al., 2015). The lack of recognition of dementia as a terminal illness, coupled with the lack of advanced care planning also reduces the individual’s autonomy. Consequently, a person could be denied the opportunity to make decisions regarding their preferences and to make decisions regarding care in accordance with their wishes, even if capacity is lost (Dening et al., 2012).

Mitchell et al. (2004) suggest that determining care tailored for end of life and dementia, deserves the attention of health care providers and policy makers (Mitchell et al., 2004). Davies et al. (2014 identified that the majority of people with advanced dementia die in care home placements, consequently end-of-life care is in fact predominantly provided to PLWD in care homes. Reports have identified that care staff have received little training in recognising end of life and in supporting those needs. Furthermore, it is suggested that palliative care services are fragmented, which creates further difficulties for care homes, who are already isolated from the wider networks of services (Lloyd-Williams et al., 2014). Studies in the UK have found a lack of collaboration between care homes and local level services, and collaborations between care services are vulnerable to breakdown, due to high staff turnover (Dening et al., 2012). Where specialist support could have been implemented from hospices into care homes, research has found the support is sought often in response to a crisis, rather than resulting from advanced care planning (Froggatt et al., 2002).

The Key Stakeholders

Families and their continued role as carers in care homes

A wealth of literature now exists on the involvement of families in care homes and their continued role as carers, despite care home placement, disputing the notion from earlier research suggesting families simply abandoned their relatives following care home admission (Hook et al., 1982; Rowles & High, 1996). Families are a fundamental part of the care provision and contribute significantly to the QoL of PLWD in care homes (LaBrake, 1996; Zimmerman et al., 2005). Previous research suggests that families are able to provide the biographical background for residents, assist with decision-making and care planning, provide personal and social care, and act as an advocate for their relative (Adams & Gardiner, 2005; Gaugler et al., 2004; Gaugler, 2005; Tornatore & Grant, 2002).

For many families, care home placement is not their preferred option for their relative, however with the progression of the illness, they may be unable to meet care needs at home and so have to accept alternative care (Woods et al., 2008). Families often wrestle with the decision to move their relative into care home placement, bringing feelings of loss, guilt, anxiety (Woods et al., 2008) and continued strain (Whitlatch et al., 2001). However, these feelings are not specific to the initial period after care home placement, families continue to experience feelings of strain and anxiety throughout placement (Grant et al., 2002). Despite the care home possibly relieving families of a number of their caregiving duties, the care home placement often introduces new challenges for families as they adapt and their roles and responsibilities shift (Gaugler et al., 2000). In addition to adapting to their new role, families are now reliant on the care staff at the care home, and their relationships and interactions with them can have a powerful impact on their well-being (Gaugler et al., 2000; Gaugler, 2005; Whitlach et al., 2001). Previous studies identified that where care home staff cared for families' well-being as well as for the residents living with dementia, they were most likely to establish good relations with the families (Gaugler, 2005). However, the impact of the relationships between family members and care home staff is not restricted to the family member, but also extends to the well-being of and stressors on care home staff (Abrahamson et al., 2009; Zimmerman et al., 2005).

Personhood and experiences of care home staff

The personhood of the care staff is often overlooked. Although they play a pivotal role in residents' daily lived experiences and well-being, they are often afforded little respect and recognition (Cooke, 2018; Fetherstonhaugh et al., 2016; Scales et al., 2017), with even less attention being paid to those caring for PLWD in care homes (Goldberg et al., 2013).

Care home staff may experience high role burden associated with demanding working conditions, staff shortages, very low pay and limited professional development opportunities and their lack of involvement in formal assessment and care-planning processes (Cooper et al., 2016; Kadri et al., 2018; Killett et al., 2016). Care staff face organisational constraints, having to juggle expectations of the care home organisation, residents and relatives. Often, they are trying to meet the personalised needs of the residents but coming up against demands of the organisation that may not allow them to fulfil their desired caregiving role. Despite an expectation to support residents as individuals and support QoL, it is expected that they perform their duties in a standardised form (Cooke, 2018; Kadri et al., 2018). A study found care staff explicitly going against organisational procedures as their strategy to provide personalised care, as the procedures given by the home did not meet the person-centred needs of the residents, despite the increased risk of disciplinary action or being seen as disruptive (Kontos et al., 2010).

In delivering quality care for PLWD in care homes, research suggests that where care staff experience higher levels of burnout and stress at work, it ultimately affects the care that they are able to provide the residents (Cooper et al., 2016; Kadri et al., 2018). Accordingly, if residents' lived experiences are to be improved, greater attention must be paid to experiences of staff providing front line care (Cooke et al., 2018). Although previous research does exist indicating the stressors and complexities of the staff's caregiving role, the motivation has often been centred on improving productivity and retention, not the personal outcomes for the care staff (Kadri et al., 2018).

Quality of life, well-being and human rights

Quality of Life

Quality of Life – concepts and definition

Quality of life is a complex and multifaceted concept, which continues to evolve in definition and has multiple interpretations. Nevertheless, it is important to understand factors which affect an individual's QoL. The concepts of QoL vary, from those with a focus on social, environmental and physical well-being to those that focus on the impact of a person's health on their ability to live a fulfilling life, and aspects of life such as income and social support. However, these elements may be excluded when dealing with QoL and disease where the primary focus is on disease related aspects and well-being. For this purpose, the term 'health related quality of life' was coined (HRQoL, Albert et al., 2001). HRQoL has been defined as the way health is estimated to affect QoL, including domains relating to physical, mental, emotional and social functioning. This is a narrow formulation, however, and given the pervasive effects of dementia, there is likely to be considerable overlap between specific HRQoL and more generic components of QoL (Wilson & Cleary, 1995). The World Health Organisation defines QoL much more broadly as:

"an individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment" (World Health Organization, 1995, p1).

Quality of life and dementia

The multiple definitions and complexity of quality of life makes its measurement and its inclusion in research complex. The standard definitions emphasise the subjective experience of quality of life, highlighted by the World Health Organization (WHOQOL Group, 1995) definition above, which frames quality of life as an individual's perception and personal expectations. Furthermore, there is even less certainty regarding quality of life for an individual living with dementia, with cognitive decline having a profound impact on HRQoL, which is now recognised as a valued health outcome measure in dementia (Landeiro et al., 2017).

Whilst there is a range of domains identified as part of the QoL construct, broader definitions are less certain. This may be a result of blurred boundaries where multiple domains are included and then coupled with the impact of dementia (Brown, 2016). There is no absolute theoretical model underlying the conceptualisation and assessment of QoL in dementia and a consensus about how to define and measure QoL is still widely debated. However, in relation to dementia, Lawton's contribution is widely recognised. Lawton's influential framework defines QoL as "multidimensional evaluation, by both intra-personal and social normative criteria, of the person environment system" (Lawton, 1991, p.6). Lawton argued that QoL is not one dimension but rather a collection of dimensions; his definition of QoL asserts that QoL is made up of subjective and objective dimensions, which are all important for QoL (Lawton, 1991:6). The dimensions are 'arranged' in a continuum of objective (objective environment, behavioural competence) and subjective (perceived quality of life, psychological well-being) dimensions. The framework is characterized by socio-normative approaches in the objective dimensions and individualistic approaches for the subjective dimensions (Netuveli and Blane, 2008).

Quality of life and advanced dementia

Interest around QoL has grown with it becoming increasingly recognised as an important clinical and policy issue. Despite this, still little is known about QoL for individuals living with advanced dementia – a population possibly unable to give their own views about their QoL and possibly having least control over their environment (Cordner et al., 2010). Whilst conceptualising and measuring QoL in advanced dementia is challenging, and definitions are lacking, some indications of features that may be important are emerging, such as social contact, psychological needs being met, attachment, affect and the opportunity to take part in meaningful and pleasurable activities (Volicer, 2007; 2016). For example, social contact, interactions, and communication at a basic level including touch (Brooker et al., 1997) elicited responses, such as smiling, babbling, laughter, eye-gaze and reciprocity that have been termed as 'happy behaviour' (Astell & Ellis, 2006; Ellis & Astell, 2017).

Measuring quality of life and dementia

In recent years, a focus on quality of life (QoL) has become increasingly prevalent within the study of dementia, giving individuals living with the illness, quite rightly, centre stage to highlight their views and experiences. Measuring QoL of people living with dementia highlights important aspects of living with the illness and supports the knowledge of healthcare services and social care organisations. Further, measuring QoL has cost-effective advantages for healthcare services and social care support organisations (Bowling et al., 2015) and for evaluating effectiveness of interventions in care home settings (Aspden et al., 2014).

Although participants may usually, and ideally, rate their own individual QoL, it is crucial not to overlook the experiences of those living with advanced dementia, who may have limited communication ability, and may be unable to provide a self-rating (Diaz-Redondo et al., 2014). In this instance, proxy measures are commonly employed to provide QoL ratings on behalf of the individual. However, this is not without difficulty, as proxy-rating raises its own challenges concerning accuracy and reliability (Griffiths et al., 2020). Previous research studies indicate lower ratings of QoL are given by proxy-raters in dementia research, compared with those of the individual living with the illness, with low to moderate correlations between self-reported, relative-proxy and staff-proxy ratings, indicating a limited level of agreement (Cooper et al., 2018).

The majority of QoL research has focused on people living with the earlier stages of dementia, where individuals are able to provide their own ratings of QoL (Griffiths et al., 2020). However, structured direct observations have also been employed to provide indicators of QoL, for those living with advanced stages of dementia, who may be unable to report their own QoL (Griffiths et al., 2020) and this may be a feasible alternative to, or addition to, proxy ratings.

Measuring QoL has multiple advantages for supporting clinical practice and research outcomes in care home settings and should be a priority to promote and maintain the QoL of individuals and to understand as much as possible, the factors that may contribute or detract from QoL (Clare et al., 2014). Several models of QoL exist which could possibly be implemented to support our understanding of QoL in advanced dementia. For example, Lawton’s (1997) framework for QoL in dementia, mentioned above, includes four factors contributing to overall QoL: behavioural competence, perceived QoL, objective environments and psychological well-being (Netuveli & Blane 2008), only one of which (perceived QoL) would require self-report.

As well as generic measures of QoL and HRQoL, a number of dementia-specific QoL measures are now available (discussed further in Chapter 2). Generic measures have the advantage of allowing comparison with the general population and/or other health conditions, whilst dementia-specific measures offer the potential to focus on those aspects of life of particular importance to those living with dementia (Banerjee et al., 2009). Advanced dementia is likely to pose a challenge for measures of both types, in view of the difficulty with self-report and the lack of clarity regarding what may underpin QoL in advanced dementia.

Well-being

Well-being - general definition and concepts

Well-being is defined by the Oxford English Dictionary as “The state of being comfortable, healthy, or happy” (Oxford University Press, 2015). However, well-being is a much broader concept than moment-to-moment happiness. Whilst it includes happiness, it also encompasses factors such as fulfilment, sense of purpose and how individuals evaluate their life satisfaction as a whole. There is no one single definition of well-being, but a general agreement on factors which contribute to achieving well-being. Although well-being is recognised as a complex and multidimensional concept with many definitions, part of the value is people intuitively understanding the significance of well-being, despite no single universal definition.

A review conducted by Dodge and colleagues (2012) highlighted the lack of clear definition of well-being referring to previous research focusing on the dimensions rather than the definition. They proposed a definition of well-being as the “balance between an individual’s resource pool and challenges faced” (p.230). Dodge et al. (2012) give a representation of a seesaw, with psychological, social, and physical resources on one side and psychological, social, and physical challenges on the other. The idea of a stable well-being is where an individual is equipped with the resources required to meet challenges they encounter and where there are more resources than challenges, the seesaw rises and therefore well-being is improved. Conversely, where an individual faces more challenges than resources their well-being will decrease. The authors’ state that this definition of well-being is easily understood, applicable to all and can be easily measured (Dodge et al., 2012).

Subjective well-being can then be seen as both a positive cognitive appraisal of one’s current situation and the experience of an appropriate balance of positive and negative emotions (Diener & Chan, 2011). Subjective perceptions of satisfaction with life reflect the experience of meaning and purpose, the ability to experience continued personal growth, a sense of being in control of one’s life, active social participation and happiness (St. John & Montgomery, 2010). Ryff (1989, 1995) proposes a six-factor model focusing on what it means to be mentally healthy and the determinants of positive psychological functioning. The components of the six-factor model are set out in Table 1.1. (see also Ryff & Keyes, 1995) and indicate how wide-ranging this construct may be.

Table 1.1 Ryff's (1995) six-factor model of psychological well-being

Psychological aspects of well-being
Sense of purpose
Self-Growth
Acceptance
Mastery of the environment
Positive relationships
Autonomy

Well-being and dementia

The concept of social health by Huber et al. (2011) suggests how an individual experiences well-being regardless of illness by maintaining a balance between opportunities and limitations in the context of social and environmental challenges (Huber et al., 2011). Similarly, Kitwood's model of personhood (1997) emphasises the way in which interactions and environments contribute to enhancing or detracting from well-being for people with dementia. Within Kitwood's person centred care approach, people living with dementia were given recognition as unique individuals. Kitwood shed a light on people's experiences, outside of the vision of PLWD as recipients of care and presented a paradigm where the person comes first (Kitwood, 1997). He also highlighted how people's experiences were influenced by external factors such as receiving formal care, and how personhood is supported by others (Kitwood, 1997). More recently a review of qualitative research conducted by Wolverson and colleagues (2016) highlighted the presence and nature of positive lived experiences, for individuals living with dementia. The given accounts of positive lived experiences were grouped into three overlapping themes: 'engaging with life in ageing', whereby people with dementia may seek continued engagement, enjoyment and social networks; 'engaging with dementia', a continuation of engaging with life and making efforts to live well despite a diagnosis, engaging in humour and positive thinking to cope with a diagnosis; and 'identity and growth', where individuals maintain a positive identity through positive life review, acknowledging their continued sense of self and meaning as an outcome of having a diagnosis of dementia. Gaining an understanding of positive lived experiences of PLWD and the strengths and capabilities people retain will have significant implications for promoting and maintaining well-being and QoL in dementia care (Moniz-Cook, Vernooij-Dassen, Woods, & Orrell, 2011).

Person centred care and well-being in advanced dementia

Important predictors of well-being amongst older people are perceived health, functional capacity, social relationships, an active life and spiritual beliefs (George, 2010). However, less is known about factors which enable and support well-being for individuals living with dementia and existing models are ‘beset with contradictions and inconsistencies’ (Cook, 2008, p. 4). Volicer and colleagues (1999) developed a six-factor model of psychological well-being in advanced dementia, focusing on opposite poles of emotional states: happy–sad, engaged–withdrawn, calm–agitated, limited to affective domains (Ettema et al., 2005). Ettema and colleagues (2005) suggest introducing the concept of adaptation to the illness, building on the work of Lawton (1995), which is possibly tailored towards people in the earlier stages of the illness (Brown, 2016). However, Ettema et al. (2005) suggest observation of people in advanced stages of the illness may demonstrate a level of adaptation to the illness, based on their behavioural responses.

It is important to note that whilst we might observe that a person with advanced dementia appears to be happy, the six components highlighted in Ryff’s (1995) model may be more difficult to ascertain or even envisage in the context of severe impairments in cognition and communication. Kitwood and Bredin (1992) identify 12 potential indicators of well-being (Table 1.2) that contribute to personhood in dementia, including self-esteem, a sense of agency or control in one’s life, initiating social contact and humour. Many of these indicators can be observed in people living with advanced dementia, despite limited communication abilities.

These indicators provide a potential person-centred framework for observing well-being in advanced dementia, where self-report may not be feasible. Kitwood (1992) summarises these indicators of well-being in people living with dementia as being characterised by feelings of worth, hope and agency, and by social confidence. These could be seen as mapping to some extent onto Ryff’s model, with worth reflecting acceptance and self-growth; hope giving a sense of purpose; agency seen in autonomy and environmental mastery; and social confidence evident in positive relationships. In relation to dementia, people living with the illness will more than ever come to depend on others not only for support, but also to provide a balance between their capabilities, capacities and limitations (Vernooij-Dassen et al., 2019).

Table 1.2 Indicators of well-being in dementia (Kitwood & Bredin, 1992)

Kitwood & Bredin (1992) Indicators of Well-being	
The assertion of desire or will	The individual expresses their desire and fulfils their intentions
The ability to experience and express a range of emotions (both positive and negative)	The individual is given the opportunity to experience and express their emotions freely
Initiation of social contact	The individual looks for opportunity to socialise and interact with others
Affectional warmth	The individual looks for opportunity to provide comfort and affection
Social sensitivity	The individual expresses their understanding and sensitivity towards a situation
Self-respect	The individual expresses pride and confidence in him/herself
Acceptance of others living with dementia	The individual shows acceptance of others around them
Humour	The individual experiences and attempts to provoke laughter
Creativity and self-expression	The individual asserts their own creativity in various forms and expresses him/herself through ideas, emotion and through creative methods
Showing evident pleasure	The individual expresses and responds positively to a situation. Expressions of happiness and joy are shown openly
Helpfulness	The individual shows willingness to assist others
Relaxation	The individual engages in behaviours which allow them to feel free from tension

Human rights

Human rights – definitions and concepts

There are many definitions of human rights. The definition of human rights given by the UK's Equality and Human Rights Commission (EHRC, 2010, P6) states that:

'Human rights are a set of basic rights and freedoms that everyone is entitled to, regardless of who they are. They are about how the State must treat you. They recognize that everyone is of equal value, has the right to make their own decisions and should be treated with fairness, dignity, and

respect. Human Rights have been written down in international agreements such as the Universal Declaration of Human Rights (1948) and the European Convention on Human Rights (1950).'

Human rights are universal and belong to everyone. Every individual has the right to life and liberty, freedom from slavery and torture, freedom of opinion and expression, the right to occupation, and many more. These basic rights are based on shared values such as dignity, fairness, equality, respect and independence. Human rights can never be taken away from an individual, although they can sometimes be 'limited', meaning that an individual's rights have boundaries in certain defined circumstances, for legitimate reasons, such as protection of health or public safety (British Institute of Human Rights, 2010).

Human rights and dementia

Dementia as a human rights issue has lacked attention in the past, but, in recent years, there has been growing recognition of the rights of people living with dementia, as they have been highlighted by people living with dementia, family carers and Alzheimer's Societies, who have campaigned for a human rights approach (Alzheimer Europe, 2017; Dementia Alliance International, 2016).

Human rights are recognised in health and social care, however they have been underrepresented in the planning and delivery of dementia care (Kelly & Innes, 2013). People living with dementia may lack the ability to report their experiences, challenge decisions and raise their concerns. In many cases, PLWD are faced with indirect discrimination, where they are disadvantaged by policies and procedures of organisations and services (DEEP 2016; Kelly & Innes, 2013).

Disability rights and dementia

Historically it has been recognised that people with disabilities require legislation to have their rights upheld, but the inclusion of dementia as a disability in this context has been slow to evolve (Alzheimer Europe 2017; DEEP, 2016; Dixon et al., 2018). The Convention on the Rights of Persons with Disabilities (CRPD) was introduced in 2006, to promote and protect the rights of people with disabilities. The purpose of the CRPD is to ensure that individuals with disabilities enjoy all aspects of human rights and freedoms under the law. The CRPD explicitly states how all rights apply to people with disabilities of all types and identifies where adaptations must be implemented for people living with disabilities, ensuring that they can exercise their rights, and where protection of their rights must be reinforced, should they have been subject to discrimination (Mental Health Foundation 2015).

Although framing dementia as a disability is not an entirely new concept (Blackman et al., 2003; Cahill, 2018; Marshall 1998), and despite a strong commitment for a positive movement for people with disabilities, there is a lack of consistency across organisations and services, with implementation not always effective or appropriate to all disabilities. Often PLWD are not having their disability needs met (Alzheimer Europe 2017; DEEP, 2016). The view of dementia largely as a health issue, primarily as a brain disease, limits the advantages of viewing the illness as a disability. The range of challenges are not considered, such as being assumed to lack capacity, without assessment or reasonable adjustment, pressured into leaving work, denied exemption from the 'Work Capability Assessment' and access to suitable transport and services (All-Party Parliamentary Group on Dementia, 2019). Furthermore, PLWD often do not identify themselves as individuals living with a disability, increasing missed opportunities and raising further barriers (Alzheimer Europe, 2017; DEEP, 2019). There is also little evidence to show how PLWD utilise national legislation (Alzheimer Europe, 2017).

Taking rights forward at a local level, the DEEP network, (Dementia Engagement and Empowerment Project) have been campaigning and raising awareness of the rights of PLWD, which affect their daily lives. The group have engaged with local and national government to lobby for changes in accessibility for PLWD, and to increase knowledge and awareness on promoting rights and equality for PLWD. The DEEP network specifically worked on a project 'Our Right to Get Out and About' focusing on the accessibility for PLWD of public transport, to consider cognitive impairments and experiences of those who are living with dementia (DEEP, 2019).

Human rights and advanced dementia

Despite the successes of groups such as the DEEP network, people living in the later stages may not have the ability to independently advocate for their own rights and may become completely dependent on others to advocate on their behalf. For many people with advanced dementia, a family carer may be available and willing to take on this role. However, family relationships are not always positive in nature and elder abuse is known to be experienced by a significant number of people living with dementia (see section 'Complex family relationships' in Chapter 8). Loss of dignity and freedoms can occur within the family context, and the availability of a relative is no guarantee that the person will have an advocate for their rights or their best interests.

In cases where PLWD are living in a care home placement, individuals will not only be dependent on any relatives who may be involved (for better or for worse) but they will also depend on their professional caregivers, the care home staff, to promote and maintain their rights. In cases where individuals do not have family members to advocate for them, they will be completely reliant on their professional caregivers, unless there is access to an independent advocacy service (as envisaged for example, in the Mental Capacity Act). There is still much work required to highlight experiences of those who are unable to advocate for themselves, whose experiences may be very different from an individual who is able to self-advocate.

Helpful principles underpinning a human rights perspective, building on the coming together of core values, have been developed that are applicable to dementia care, with the acronym 'FREIDA' (see Table 1.3).

Table 1.3 FREIDA Principles

FREIDA principles (Curtis & Exworthy, 2010)
Fairness
Respect
Equality
Identity
Dignity
Autonomy

The emphasis is on maintaining and promoting individuals' lifelong rights, promoting development and growth and working towards reducing ill-being (Kinderman, 2007; BPS, 2009). There is clear overlap with Kitwood's work on person-centred values (Kitwood, 1997), respecting and empowering the individual, but it also provides an ethical and legal framework (Kelly & Innes, 2013), challenging inequality and the acceptance of less than excellent care for people living with dementia, simply because it has become standard practice (Kelly & Innes, 2013).

How do these three constructs fit together?

Quality of life, Well-being and Human Rights

Well-being and quality of life are widely discussed, and often conflated, in health and social sciences. The consensus is that well-being is only one dimension of QoL, to be considered alongside external influencers such as environmental factors (Lawton, 1983, 1994; Olsen & Misajon, 2020) highlighted by Lawton's QoL framework, referring to well-being as one of the necessary dimensions in achieving overall QoL. The concept of QoL dates back to the 1947 World Health Organization (WHO) definition of health as a "state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity (WHO, 1947) and the use of the term "well-being" and QoL interchangeably in the history of QoL has caused some confusion. However, the idea of "well-being" is useful in regard to relating to everyday life and steering away from the medicalisation of quality of life (Dodge et al., 2012).

In terms of quality of life, well-being and human rights, there are 16 basic rights (Articles) within the European Convention on Human Rights, referring to issues not only concerning life and death but everyday life: our beliefs, our right to family life, freedom of expression and other basic entitlements. Cahill (2018) argues that the thinking around human rights needs to address everyday issues, as they are a crucial part of having our individual and basic needs met as humans that are essential to our well-being. Lawton also discussed QoL domains such as healthcare, family life, beliefs and housing needs, which are well known within the Human Rights Act. The current discourse surrounding human rights has been problematised and centred on 'big ticket' issues linked with abuse scandals and poor care provision (Cahill, 2018). Within the field of dementia, human rights discourse has been largely centred on capacity and the diagnosis of dementia has too often been taken to implicitly imply the absence of capacity, contributing to the lack of human rights-based approaches within this field. As a result, the current focus does not reflect human rights within everyday life experiences, such as an individual's right to exercise their own choice and decision-making on matters crucial for their independence, dignity, autonomy and well-being (Cahill, 2018).

As human rights are often coupled with legal frameworks and the 'dark' side of health and social care, perhaps their potential as a building block in providing quality of life and well-being is not sufficiently considered. However, the recognition of human rights in terms of achieving QoL and promoting well-being is fundamental as rights are absolute, and bound by a legal framework, requiring legal intervention.

Quality of Care as the linking factor

In long-term care facilities, PLWAD (people living with advanced dementia) will become increasingly dependent on the care staff for support. Through their contact with the PLWAD, care staff gain knowledge of the individual with dementia such as preferences and behaviours. They are often the first to notice changes, signs of illness, pain and discomfort or decline (Jansen et al., 2017) all of which are associated with person centeredness, quality of care (QoC) and influence quality of life (Beernes et al., 2016).

Quality of care indicators are objective measures that reflect care standards and are used as guides to monitor and evaluate the QoC (Bökberg et al., 2017). QoC indicators identify care procedures which can influence a person’s wellbeing, health and/or QoL. Quality of care indicators can also increase understanding of the individual needs that can lead to changes in care planning and provision (Hutnik et al., 2012; Bökberg et al., 2017). One indicator of QoC is ‘satisfaction with care’. There is no universally accepted definition of or measure for satisfaction with care, but a care recipient’s satisfaction is none the less an important aspect of QoC (Bökberg et al., 2017).

Important QoC indicators in the care of older people are pain, falls, mood decline, pressure ulcers and weight loss, indicating deterioration in chronic illness such as dementia (Holwerda et al., 2012; Lim et al., 2011). High quality care identifies these factors and responds with appropriate interventions for the individual to prevent or ameliorate their effects. Aspects of care relating directly to QoL such as pain assessment and effective pain management have the potential to maximise QoL at the advanced stages of dementia. Where individuals are at the later stages of the illness, self-reporting of discomfort may be difficult, but behaviours are observable and individuals will rely on care staff to ‘pick up on’ the ‘signs’ of pain and discomfort (Cordner et al., 2010).

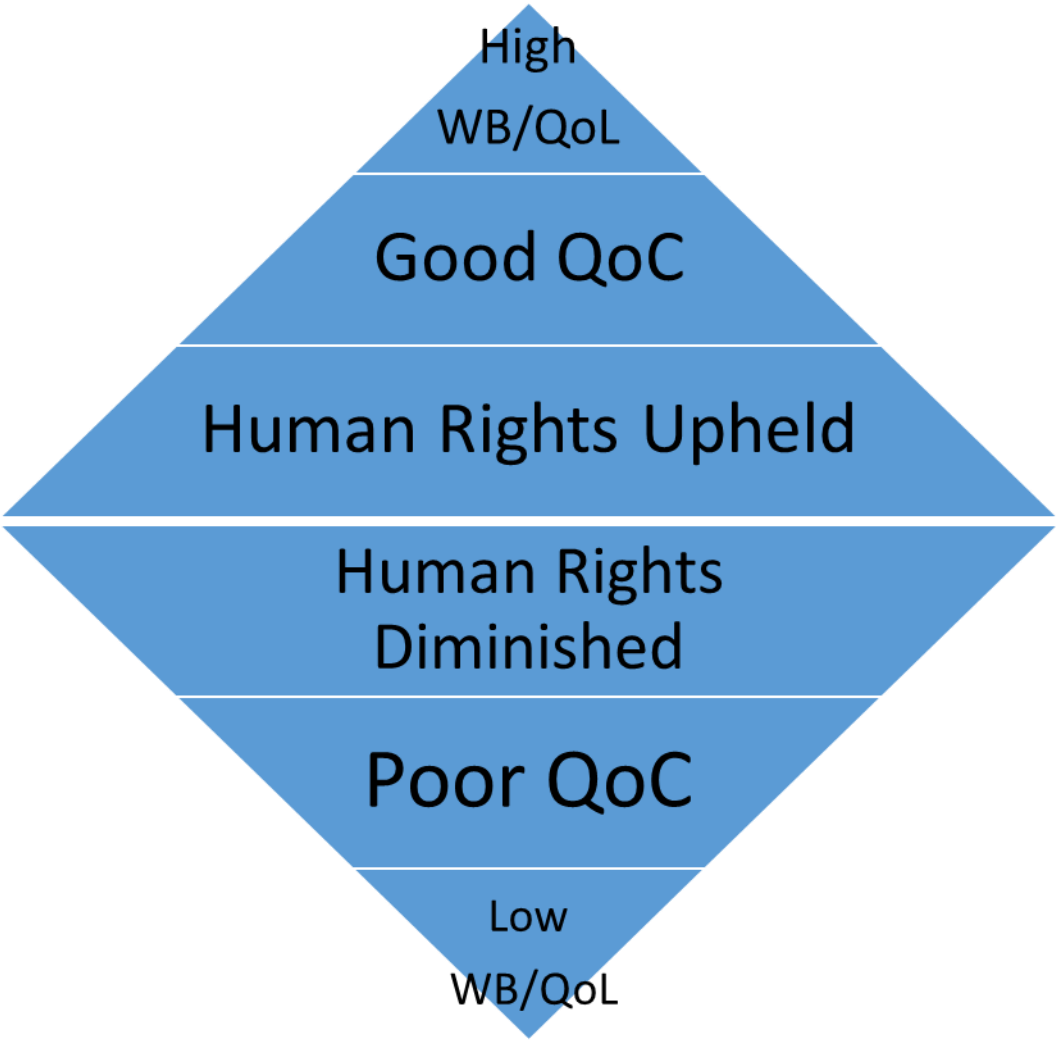
QoL and well-being in persons with advanced dementia is therefore in large part dependent on the QoC they receive (Bökberg et al., 2017). This is evident, for example, in the widely used observational procedure, Dementia Care Mapping (Kitwood & Bredin, 1992; discussed in more detail in Chapter 2). Although often seen as an indicator of well-being for people with dementia, ratings depend on the quality of care and input from care staff, and there has been debate as to whether it measures QoL, QoC or both (e.g. Brooker, 2005).

As dementia progresses, individuals become increasingly dependent on whoever is providing care to support their needs and it is here where their human rights become at risk, as they are reliant on others to provide care which upholds their dignity, is respectful and promotes autonomy (Butchard & Kinderman, 2019). It is often just accepted when an individual is living with dementia that their QoL will be low and therefore very little else is aimed for. As a result, there is a sense of hopelessness around maintaining and promoting QoL for PLWD. This can lead to task orientated care, driven by the organisation’s expectations rather than a person-centred approach, creating a culture, which does not consider the person first, which in turn is known to adversely affect quality of life for people with dementia (Farina et al., 2019). Such a culture is at odds with the human rights set out, for example, in the FREIDA framework.

Care provision for PLWAD is not without complexity, given the variation in how the illness manifests and progresses, often alongside co-morbidities associated with ageing, and how individual preferences and wishes vary. Such complexity determines the diversity of care needs that people require ranging from more basic (e.g. assistance with self-care) to psychosocial needs (e.g. being part of a community; Fusar-Poli et al., 2020). The traditional service-led approach to care, where needs are assessed against the organisation's current service provision, is not able to meet such complexity. Where the care is led by meeting the organisation's policies and procedures only, PLWAD will face the totality of their needs remaining unmet, despite physical care needs being upheld. High QoC provision for a PLWAD will be tailored to the individual's needs as a whole person (Gilster et al., 2018), as is consistent with an approach based on human rights (Butchard & Kinderman, 2019).

Human rights principles are fundamental to the provision of high quality public services, with the aim that individuals are treated fairly, equally and with dignity and respect. In order to provide high QoC provision to PLWAD, care staff need to address individuals' basic human rights, which are often under-acknowledged and unspoken of until there is awareness that they are being significantly breached (Cahill, 2018). Where high QoC is being provided, not only are individual's physical needs being met, but the person's identity is maintained and care provision is centred around the individual's needs as a whole person, contributing to their well-being and overall QoL. Care staff will play crucial roles in sustaining the identity and quality of life of individuals living with dementia, especially as the illness progresses to the advanced stage (Gilster et al., 2018). Where the individual becomes fully dependent on those providing care to advocate on their behalf, becoming completely dependent on them to communicate their wishes, they will also be dependent on them having whole person knowledge of the individual they are caring for (Gilster et al., 2018). In summary, in advanced dementia quality of life and well-being will become almost completely dependent on quality of care. Quality of care will reflect the extent to which the individual's human rights are being upheld. This is shown diagrammatically in Figure 1.1.

Figure 1.1 Relationship of Human Rights with Quality of Life and Well-being is driven by Quality of Care (QoC)



Aim of thesis

The overall aim of this thesis is to explore and increase understanding of quality of life, well-being and human rights of care home residents living with advanced dementia. This addresses the question of how personalised care can be achieved when the person is completely dependent on others for care and may no longer be able to verbally communicate their wishes. In order to achieve this aim, a systematic review and two empirical studies in a total of four care homes providing care for people with advanced dementia were undertaken.

The specific aims were then:

1) To review and appraise published measures and methods of evaluating QoL, suitable for individuals with advanced dementia in a care home context, with a view to identifying those that were most useful and potentially applicable to the empirical work to be undertaken.

2) To explore the lived experiences of residents with advanced dementia in care homes

3) To explore the perspectives of relatives of residents with advanced dementia on the quality of life and well-being of residents and how this is expressed and communicated, their satisfaction with care and their own well-being.

4) To explore the perspectives of staff providing care for people with advanced dementia in care homes on the quality of life and well-being of residents and how this is expressed and communicated, on the involvement of families and on their own well-being.

5) To investigate how human rights of residents are upheld and how family members and staff members deal with surrogate decision-making, including consideration of how a person's rights and choices can continue to be achieved in situations where the person may no longer be able to verbally communicate their wishes.

Signposting the thesis

My work presented in this thesis commenced with funding for a one-year (2016-2017) Master's by Research project '*The quality of life of people living with advanced dementia: A pilot study'.* This involved a partnership with Fairways Care as the business partner for EU Knowledge Economy Skills (KESS 2) funding. My supervisors developed the successful proposal for this funding prior to my appointment. During this initial year, the work I undertook was guided by the proposal and by discussions with Fairways Care regarding research that would be of interest and use to them. Hence, I developed and carried out a systematic review of quality of life measures for people with advanced dementia, reported in Chapter 2, and planned and undertook the field-work for the initial study (Study 1), carried out in two purpose-built Fairways Care care-homes for people with dementia. The results of Study 1 are presented in Chapters 4 and 5 and I have been able to publish these in peer-reviewed journals during the duration of the project. In Chapter 4, I present the perspectives of relatives and staff, whereas in Chapter 5 I present perspectives of residents, focusing on two of the residents whom I studied in depth. The project was then up-graded into a PhD project, for a further 2 years, with the Drapers Charity now partnering KESS as the main funder. This allowed me to develop the project further, using Study 1 as a springboard to go beyond the initial proposal, without the requirement of reporting to a business partner. Accordingly, in Study 2, I built on and extended the initial work with relatives and staff, designing and carrying out a further empirical study in two further care homes, neither purpose built for dementia care, one of which had recently come under the ownership of Fairways Care and one which was under independent ownership. Study 2 was a mixed-methods study, and, for convenience, I present the quantitative data in Chapter 6 and the qualitative data in Chapter 7. In Chapter 3 I provide an overview of the philosophical, theoretical, methodological and ethical considerations underlying the two empirical studies. In Chapter 8 I provide a general Discussion of the work undertaken and present some conclusions and recommendations.

In relation to my substantive role in the research reported in this thesis, for the literature review, I planned and carried out the literature searches on the proposed topic, carried out the screening leading to the selection of the included studies and carried out quality assessments on these papers. One of my supervisors (KA-S) acted as second rater for the quality assessments. For the empirical studies I planned and undertook all the field work, including interviews and observations; transcribed all recordings and entered qualitative data into the qualitative data analysis software tool used and quantitative data into SPSS. I undertook the initial qualitative and quantitative analyses and, for Study 2, convened a qualitative analysis workshop with my supervisors to assist me in developing a deeper, richer understanding of the data across cases. Throughout the thesis I produced and refined drafts of all chapters, including those published, benefiting from feedback and suggestions from my supervisors (and reviewers in relation to Chapters 4 and 5).

Personal Reflection

As this research involves extensive qualitative and observational work, with the researcher immersed in care home environments providing care for people with advanced dementia, it is appropriate to reflect from the outset on the experiences that have shaped my approach to the area.

My research was motivated by an interest in understanding of QoL and dementia, and the impact of cognitive impairment on the brain and behaviour. Furthermore, I was particularly interested in the daily-lived experiences of people living with dementia in care settings. Prior to this research, I had completed my undergraduate studies in Psychology with Neuroscience.

Throughout my childhood, my mother worked at a care home and at a local community hospital before joining a high dependency team. Where my parents' work patterns clashed, it was not uncommon for me to spend time at my mother's workplace. As a child, everyone always welcomed me, and I was encouraged to have my tea with the patients/residents, this was a natural part of my childhood. I have always felt 'at home' in care environments.

On a more personal level, my father's stepfather (referred to as Taid O.G) was diagnosed with dementia fifteen years ago. As an individual, he had a long and successful career in the Royal Navy and had travelled the world. Taid O.G had always been a very active man, who would spend much of his time outdoors, a keen walker who played an active role in the community, always with a story to tell. However, as Taid O.G's symptoms became more apparent, he was not only faced with the challenges of the illness, but with the lack of understanding that surrounded dementia in the community at the time. In addition, never faced with a caring role, my father struggled, not only to come to terms with his condition, but with the responsibility that had now been placed upon him, from family member to carer and advocate overnight. Despite the work in the dementia field having progressed, I felt the stigma attached to the illness was apparent. The lack of awareness of dementia in the community caused further upset, with people insensitive to the symptoms of his illness and passing judgement.

As Taid O.G's symptoms progressed, he sadly became a danger to himself; he was sectioned, and admitted to a mental health unit. From this point, he was not supported beyond the basic care routine; he was not encouraged to access the outside gardens or to remain mobile in general. Aside from sitting in a chair or upright in bed, everything seemed to be considered a 'high risk' or out of reach. During this period, strict visiting policies were still imposed and therefore he lacked any company or any familiarity for the majority of his day. This was my first ever experience of this kind, and I could not understand how a person with a dementia diagnosis specifically, was no longer seen as a person who had lived a life, a person with history, values, experiences, thoughts or wishes.

Accordingly, I brought to this research endeavour the experience of familiarity with care environments and of relating with residents and patients, tempered by an awareness of stigma and the potential for loss of personhood, in the context of what I now recognise as a 'malignant social psychology' (Kitwood, 1997b).

Chapter 2: A systematic narrative review of quality of life measures for people living with advanced dementia

Introduction

With the growing number of older people in the population, the number of people living with dementia continues to rise. Estimated figures predict 70 million people living world-wide with dementia by 2030 (Alzheimer's Disease International, 2015). The progression of dementia is often referred to in separate stages; early, mid-stage and late-stage dementia. The term 'advanced dementia' is often linked with death and dying, and therefore, attention has focused on end-of-life care. However, the symptoms in advanced dementia are complex and although the term is widely used, there is a lack of definition in practice, policy and research literature (Hanson et al., 2017). The definition of advanced dementia from the recent European Palliare Project (Tolson et al., 2016), developed through the involvement of professional health care practitioners and family carers, quoted in Chapter 1 of this thesis, emphasises this complexity, and the need for health needs to be expertly addressed, in collaboration with those providing care. The uniqueness of the experience relates to many factors, including co-morbidities, biography and personality, and the duration varies greatly, including the end stages of death and dying.

As there are currently no curative treatments, the main focus of care in dementia is to promote and maintain an optimal quality of life (Ettema et al., 2005). Ensuring quality of life (QoL) of individuals living with advanced dementia has been identified as a priority in care (World Health Organisation, 2012). Over the decades, the concept of QoL has evolved from an idealistic notion to a social construct that guides programme practices and provides useful and conceptual measurement frameworks which underpin the assessment of individuals. This construct has become the link between the general values reflected in social rights and the personal life of the individual. It has also become a vehicle through which individual empowerment and life satisfaction can be understood and enhanced (Ettema et al., 2005).

In recent years evaluating quality of life (QoL) has become increasingly prevalent within the study of dementia (Algar et al., 2016; Ettema et al., 2005; Moniz-Cook et al., 2008; Jing et al., 2016). QoL models capture the essential dimensions of an individual's life situation (Verdugo et al., 2012). Factors contributing to QoL include basic needs being met, positive relationships, medical care, and opportunities to flourish and partake in meaningful activities (Ryff & Keyes, 1995; Volicer, 2007).

However, the concept of QoL, and its interaction with health status, is not always clear and has been the subject of much debate notable for its dynamic and interchangeable terminology. Lawton (1997) states "quality of life is defined in so many ways by so many people and, regrettably, often is not defined". As discussed in Chapter 1 of this thesis, Lawton, who made a significant contribution to the field, proposed a model of 'good life' in which there are four sectors of QoL: behavioural competence, psychological well-being, perceived quality of life and objective environment. Lawton proposed that all contributors influence the self, which in turn influences the components of QoL (Lawton, 1983).

Since Lawton proposed this generic model for older people, specific approaches within dementia have been developed. These include needs-based satisfaction models, based on Maslow's hierarchy of human needs (Maslow & Lewis, 1987) for maintenance and existence (physiological, safety and security, social and belonging, ego, status and self-esteem and self-actualisation). Psychological theories place emphasis on personal growth, cognitive competence, self-efficacy, social comparisons and past and current experiences, aspirations and individual's expectations and hopes (Maslow, 1968).

Theories of well-being often fall into two groups, hedonic well-being, focused on happiness and less negative affect (e.g. Diener & Lucas 1999) and the eudemonic approach, focusing on aspects such as self-realisation and functioning as an individual (Ryff, 1989). Despite a wide range of theories, a more consistent approach is defined in positive psychology, stating:

*'well-being is not simply the absence of negative function, but rather is something more. That is, a lack of negative affect, depression, loneliness, insecurity, and illness is not the same as the presence of positive affect, happiness, social connection, trust, and wellness' (*Seligman 2011 p. 15).

Seligman's PERMA model states that flourishing is derived from five well-being pillars that make up the model's acronym (positive emotion, engagement, relationships, meaning, and accomplishment). The model refers to "flourishing" as a dynamic optimal state of psychosocial functioning, which comes from functioning well across multiple psychosocial domains (Seligman, 2011).

Kitwood's (1992) indicators of well-being in people living with dementia (see Table 1.2) resonate with positive psychology concepts. He summarises them as being characterised by feelings of worth, hope and agency, and by social confidence. However, these may be much more difficult to identify in the context of severe cognitive impairments. Volicer and Bloom-Charette (1999) identified three areas relating to QoL specifically in advanced dementia in their model of quality of life in advanced dementia. The first area is meaningful activities in the person's social and physical environment. Volicer and Bloom-Charlotte (1999) proposed this to be the most significant area of QoL as it is the most challenging to achieve in advanced dementia as the individual may be unable to initiate the interaction independently. The second aspect refers to medical factors, such as difficulties in swallowing, pain and infections. Finally, the third domain refers to psychiatric symptoms, which include functional impairment, depression and anxiety (Volicer, 1999; 2007).

Despite challenges, evaluating and understanding QoL in advanced dementia is important as those providing care regularly make decisions in part or in full on the individual's behalf and assumptions of QoL can influence decision-making and care planning (Karlawish et al., 2001). Because of the progress of the illness impairing judgment, language and insight, both professional and family caregivers often in part or in full become surrogate decision-makers, and perception of QoL is significant in the decisions they make. However, assessing the QoL through appropriate measures in cognitively impaired adults presents unique challenges. The progression of the condition means measures that were previously suitable for the individual may not be appropriate in the later stages of the condition. As people progress into the later stages and may require care home placement, it is important to consider QoL as a dynamic concept as what is important in terms of QoL may change as dementia progresses or as the individual's living environment changes (Beerens et al., 2016). Therefore, QoL assessments need to be sensitive to differences in the severity of the condition and to different lived environments when evaluating QoL in advanced dementia (Beerens et al., 2016; Bowling et al., 2015).

Although not straight forward, assessing QoL is fundamental in evaluating the outcomes of interventions and in identifying potentially modifiable factors influencing QoL (Bowling et al., 2015). Despite the challenges, many QoL measures have been developed, leading to a diverse range of indicators; broad health status, physical, mental, social functioning and health perceptions; generic measures as opposed to disease specific and global versus health-related measures. Generic QoL assessments cover a wide range of domains in a single measure, often with a primary focus on health domains. A benefit of employing generic measures is the ability for comparisons among different groups (Selai, 2001). However, the validity of employing generic measures in dementia research has been questioned (Banerjee et al., 2009; Ettema et al., 2005). Importantly, disease specific instruments may reduce patient burden and negativity by including only items relevant for a particular condition (Ettema et al., 2005). Additional benefits of using a disease-specific measure are the ability to differentiate from other disease populations and identify key predictors of QoL on items which can support further development and research within QoL of individuals living in later stages of the illness. Within advanced dementia, measures need to consider the characteristics of the particular stage and, the effects of cognitive impairments and specific problems related to the condition (Ettema et al., 2005; Missotten et al., 2016; Perales et al., 2013). Additionally, a number of measures are referred to as health-related quality of life (HRQOL) measures, which has also been known as 'patient functional status' adding further complexity to the search for an appropriate measure. According to WHO, HRQOL encompasses domains of 'physical health' 'psychological health' 'level of independence' and 'social independence'. Typical HRQOL measures, such as the SF-6D, include domains such as physical functioning, role limitations, social functioning, pain, mental health, and vitality (Brazier et al., 2002) whilst the EQ-5D lists mobility, usual-activities, self-care, pain or discomfort, and anxiety or depression (Orgeta et al., 2015).

Self-rated measurement, where an individual is able to rate their own QoL, is considered the 'gold standard' (Clare et al.,2014) in that subjective perceptions are at the heart of QoL. Research suggests many people in the early to moderate stages of dementia are indeed able to rate their own QoL (Alzheimer's Society, 2013; Banerjee et al., 2009; Clare, et al., 2014). However, it is important to consider people at the later stages of the condition who may be unable to complete self-rated measures due to the severe impairments in cognition and communication in advanced dementia (Algar et al., 2016; Clare et al., 2014). Consequently, employing self-rated measures may lead to exclusion of people in the later stages of the illness partaking in research. Accordingly, proxy- reports are often employed to measure QoL of individuals living with advanced dementia (Brod et al., 1999; Ettema et al., 2005; Logsdon et al., 1999). Proxy assessments can be completed by families, care professionals or both for people in the later stages of dementia. Rating QoL of individuals living with advanced dementia is then inferred from verbal and non-verbal behaviours that are observed and interpreted by others. However, proxy-given ratings are not without concerns, as how we, as individuals, observe and perceive these behaviours is potentially open to risk of bias. Previous studies comparing self-ratings and proxy-ratings have found discrepancies between individual rated QoL and proxy ratings, with proxy ratings indicating lower levels of QoL (Buckley et al., 2012; Clare et al., 2014; Sands et al., 2004; Zhao et al., 2012). Factors influencing lower ratings of QoL are associated with the level of dependency, cognitive impairment and particularly the proxy's level of burden and depression (Buckley et al., 2012; Conde-Sala et al., 2009; Snow et al., 2005) and the proxy's own QoL (Conde-Sala et al., 2009). Establishing observer agreement is fundamental as the way in which different observers report events can significantly impact the results (Ettema et al., 2005; Thornton et al., 2004; Volicer & Bloom-Charette, 1999). Even where the measure is based on direct observation of the person's verbal and non-verbal behaviours, inter-observer agreement is needed to agree on how behavioural definitions are to be interpreted. Any measure that relies on the judgments of raters or reviewers requires evidence that any independent, trained expert would come to the same conclusion and achieve high inter-rater reliability.

The current review aims to identify and appraise measures which are suitable for evaluating QoL of individuals living with advanced dementia. Despite increasing research on QoL and dementia, little is understood about the factors influencing QoL in the later stages of dementia and there is limited literature relating to which tool is most applicable or can be applied to care settings. This research intends to address this by identifying measures which may be of use in furthering our understanding of quality of life in advanced dementia and the factors influencing it.

Research Questions

The primary review questions are:

1. What measures are available for evaluating QoL of people living with advanced dementia?
2. What are the features of these measures in relation to their usefulness and applicability, including in care home settings.

Method

A systematic literature search was conducted using electronic databases PROQuest, ASSIA, Web of science and CINAHL on October 10th 2017 and again on May 25th 2018. The following search terms were combined 'quality of life' 'well-being' 'Alzheimer's disease' 'advanced dementia' 'severe dementia' 'dementia' 'measures' 'late stage' and 'end stage' to identify peer reviewed English language papers employing QoL measures for people living with advanced dementia. Papers were excluded if they were not in the English language, were not relevant to the search, or were not relevant to advanced dementia or were not measuring quality of life; measures for other illnesses and interventions such as tube feeding in residents living with dementia were excluded.

Identifying relevant studies

Inclusion criteria:

- English language peer reviewed articles (no date limits)
- Papers including measures of QoL applicable to PLWAD
- Supporting papers describing measures were included in addition to the primary publication of a measure

Exclusion criteria:

- Papers not in English language

- Papers not measuring QoL of PLWAD (e.g. pain assessment)
- Papers evaluating family carers' strain and family carers' QoL
- Papers judged not relevant to advanced stages of dementia (i.e. measures that had been designed/used for mild-moderate stages of dementia)

Quality evaluation

In order to evaluate the quality of the measures identified from the search, the critical appraisal tool developed by Francis et al. (2016) for this purpose was employed. This tool comprises 18 criteria, with each criterion rated met or unmet, across six quality domains: conceptual model; content validity; reliability; construct validity; scoring and interpretation; and respondent burden and presentation.

Two raters (the researcher and KA-S) first evaluated the measures independently, before reaching consensus through discussion at a meeting with a third person (BW). As recommended by Francis et al. (2016), the scores are not summed to produce an overall quality index, but rather to highlight areas of relative strength and weakness for each measure, benchmarked against accepted good practice for the development of outcome measures.

Results

The initial search resulted in 7,606 publications as shown in a flow chart (Figure 2.1), which following screening of abstracts and titles left 42 potential papers. Following full text retrieval, 29 papers were rejected, as they did not meet the inclusion criteria (Figure 2.1). In total six measures were included for appraisal described in thirteen supporting papers. The instruments found in the search were reviewed for content. Table 2.1 provides an overview and summary of the six measures found in the search.

Figure 2 1. Data Sifting**:** Flowchart of the review process

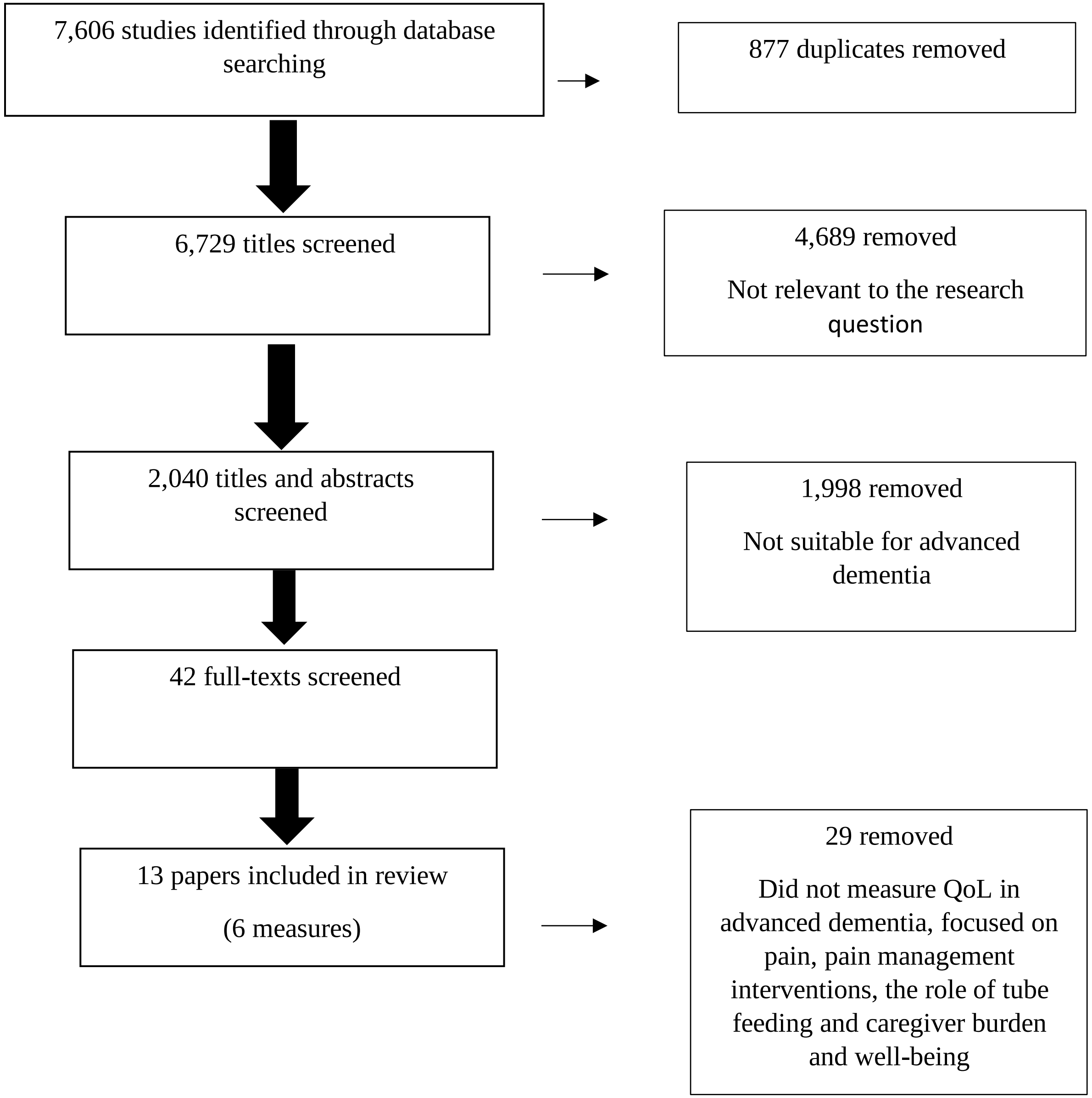


Table 2.1

Measure	Purpose of measure	Domains observed	Procedure	Key references
DCM	To identify quality of care and QoL of people living with dementia in care settings	Behavioural category codes (behaviours or activities engaged in): Articulation; Borderline; Cool; Doing for self; Expressive; Food; Going back; Intellectual; Joints; Kum and Go; Leisure; Nod: Land Of; Objects; Physical; Religion; Sexual expression; Timalation; Unresponded to; Vocational; Withstanding; Excretion; Yourself; Zero option Mood/Engagement code +5 +3 +1 considered signs of wellbeing. Signs of illbeing -1 -3 -5	Observations of five to eight people. Observation of behaviour or engaged activity engaged in, recorded every 5 minutes continuously for six hours. The observer records two codes BCC and ME for each participant. The observer records any personal distractions (PD) or Personal enhancers that occur (PE)	Kitwood & Bredin (1992)
QUALIDEM	QoL observations, rated by professional caregivers	Care relationship; Rejects help; Is Angry; Conflict with staff; Accuses others; Appreciates help s/he receives; Accepts help; Criticizes daily routine	The four response options are never, rarely, sometimes, and frequently. Scoring by the professional caregiver takes approximately 15 min	Ditcher et al. (2016)

AwareCare	Measure of behavioural responses of individuals with advanced dementia	Events that occur: Someone is nearby; Resident is touched; Resident is spoken too; Talking nearby; Loud noise; Food/Drink Introduced events: Call by name; Take hand; Introduce one object (picture, lavender pillow or textured cushion) or introduce a more personal object. Possible responses: Eyes flicker; Makes eye contact; Explores with eyes; Smiles; Frowns; Nods or shakes head; Moves head; Reaches; Grasps or holds; Moves towards; Moves away; Single words; Mumbling; Shouts or moans	Five separate 30 minute observations made in communal areas, whilst resident is awake at different times of day. A record is made of each stimulus that happens in observation session, and all responses as well as a note about the setting and the resident's behaviour during the observation period., any changes or events that happen during the observation and any behaviours not covered in the matrix	Clare et al. (2012)
QoL-D	Measure activity and affect on QoL	Positive affect; Negative affect and actions; ability to communicate; Restlessness; Attachment with others; Spontaneity; Activity. Response categories are frequently (≥3 times during the week), occasionally (≤ 3 time during the week); activities can be combined into a summary activity measure, which ranges from 0 to 30, with higher scores indicating more activity.	Questionnaire completed by a caregiver, based on responses over a period of seven days	Terada et al. (2002)

ADQRL	To assess aspects of QoL of persons living with dementia	Social interaction; Awareness of self; Feelings and mood; Enjoyment of activities; Responses to surroundings. Responses from 0-4 with higher scores indicating higher importance	Family caregivers measure responses over a two week period based on actions and observable behaviours.	Rabins et al. (1999)
QUALID	Ratings of individual's QoL during the last week, capturing the frequency of occurrences	Smiling; Sadness; Crying; Discomfort; Irritability; Calmness; Engagement; Comfort; Eating; Engaging; Interacting with others	Questionnaire rated by family carer or professional. Ratings for every domain on Likert scale 1-5 indicating never to most of the time. Possible scores 11-55, with lower scores indicating a higher QoL	Weiner et al. (2000)

Measures of QoL in advanced dementia used for staff development

Three of the identified measures had been employed to monitor staff input and interactions and aid professional development: Dementia Care Mapping (DCM; Fossey, Lee & Ballard, 2002), QUALIDEM (Ettema, et al., 2007) and AwareCare (Clare et al., 2012). It is important to note that neither the AwareCare tool nor the DCM claim to measure QoL directly. However, the DCM refers to aspects of well/ill being, and both measures share indicators of responsiveness to the environment. DCM had originally been developed to assess quality of care, but has increasingly been used as a tool in research (Algar, Woods & Windle, 2016). AwareCare was initially developed to measure awareness in people living with advanced dementia (Clare et al., 2012). It has been found that care staff are likely to distinguish between individuals who they perceive as aware and responsive, and those whom they perceive to lack awareness and responsiveness and may be less likely to interact with individuals they perceive to lack awareness. These assumptions of awareness and responsiveness therefore significantly impact well-being and QoL (Clare et al., 2014).

Dementia Care Mapping

The DCM is based on Kitwood's psychosocial theories of dementia drawing on person-centered care (Kitwood & Bredin, 1992). Recognising the person as an individual is thought to enhance well-being, whereas a depersonalizing social environment leads to ill-being (Brooker & Surr, 2006). Accordingly, person-centered care environments can maintain a person's engagement, regardless of their dementia severity. The inclusion of both positive and negative elements in the measure allows organisations to reflect on practices which promote individuals' well-being and practices which contribute to the individuals' ill-being.

The DCM incorporates both subjective QoL (well-being) and objective indicators (activity-behavioural category). A number of studies have reported that good to very good levels of inter-rater reliability (IRR) can be achieved with the DCM. Prior to using the DCM, it is recommended that mappers code participants simultaneously for at least one hour to establish an IRR of 70% agreement (Brooker & Surr, 2006; Beavis et al., 2002). The DCM is only to be used by a trained mapper, who has undertaken specific training to use the tool. The mapper must undertake a four-day training course which is priced at £975, (as of 28/04/18) facilitated by University of Bradford. The DCM requires five to eight individuals to be observed using interval coding in communal areas over a period of six hours, and two codes are used to record the observations (Fossey et al.,2002). *The Behavioural Category Code (BCC)* is an activity or behaviour observed during the time-frame. If more than one behaviour is observed during the time-frame, the mapper must decide which observed behaviour was most influential for well-being (Fossey et al., 2002). To aid this process, mappers can categorise behaviours into: Type I (Potential of well-being) and Type II (low potential of well-being). The second code: *The Well/Ill Being (WIB)* represents the judgment provided by the mapper about the individual's affective state during the time period of observation (Fossey et al., 2002). These scores are based on activity, affect, and time duration recorded in the BCC. WIB values are rated on a six point scale with -5 -3 -1 representing low well-being and +1, +3, +5 representing well-being (Sloane et al., 2007). It is noteworthy that an indeterminate '0' value is not an option.

Previous studies and research identified in this review, report concordance coefficients (for IRR) ranging from 0.70 (Brooker & Surr, 2006; Innes & Surr, 2001) to 0.85 (Edelman et al., 2005). Fossey et al. (2002) look directly at some of the psychometric properties of DCM. A good level of test-retest reliability is reported for DCM, demonstrated through good levels of agreement for considerable well-being (r=0.58) and for the well/ill-being score (r=0.55), with more moderate correlations for Activities and Social withdrawal. Inter-rater reliability for the DCM was evaluated in six care facilities (Fossey et al., 2002). Inter–rater reliability was achieved with a minimum Kappa value of >0.8 between individual raters, evaluated over a series of pilot mapping sessions.

Although not explicitly addressed by the authors, DCM demonstrates content validity in that it was established embedding Kitwood's theory of personhood and person-centered care (Brooker & Surr, 2005). Concurrent validity has also been reported for the DCM through a strong correlation between well-ill being with a QoL score derived from the Blau QoL scale (Fossey et al., 2002).

The data collected during the observations evaluates the individual's lived experiences, which is a major contributor of their QoL (Fossey et al., 2002). For training and development purposes, positive events (such as good care practice) and negative events (where a person is belittled) are documented. The additional observations collected about individuals' experiences provide care organisations with feedback about care practices and staff conduct, which can be used to aid staff development (Fossey et al., 2002). The method is very time intensive. Nevertheless, the DCM has been successfully used to examine and detect change in the QOL of people with dementia (Fossey et al., 2002; Inness & Surr, 2001), and can, due to its observational character, be potentially applied through all stages of the disease (Ettema et al., 2005; Sloane et al., 2007).

QUALIDEM

The second measure, QUALIDEM, also incorporates both aspects of well-being and ill-being and aims to divert raters away from focusing on the negative features of advanced dementia (Bouman et al., 2011). QUALIDEM is suitable for measuring QoL of individuals living in care homes, aiming to highlight that well-being is not merely the absence of distressed behaviour, including domains such as care environment and care relationship (Bouman et al., 2011). The QUALIDEM is based on an 'adaption-coping' theoretical model (Dichter et al., 2016 p.5). QoL in dementia is defined here as 'the multidimensional evaluation of the person-environment system of the individual, in terms of adaptation to the perceived consequences of the dementia' (Dichter et al., 2016 p.5). Seven adaptive tasks are seen as important components of QoL: 'Dealing with own disability', 'Developing an adequate care relationship with the staff', 'Preserving emotions', 'Preserving self-image', 'Preparing for an uncertain future', 'Developing and maintaining social relationships' and 'Dealing with the nursing home environment' (Ettema et al., 2007).

The measure consists of 37 items but a shorter version is employed for people in later stages of dementia. The QUALIDEM for advanced dementia consists of 18 observable behaviours over six homogenous subscales: Care relationship, Positive affect, Negative affect, Restless tense behaviour, Positive self-image and Social relations. Response options are; Never, Rarely, Sometimes and Frequently (Dichter et al., 2016). Additional items are being considered for further research: 'Enjoys meals' 'Does not want to eat' and 'Enjoys lying down (in bed)', as they could supplement the instrument, and are observable behaviours of people living with advanced dementia (Bouman et al., 2011).

The QUALIDEM instrument is intended to measure QoL for individuals aged sixty-five and older and whether the measure is suited to younger individuals is yet to be explored (Ditcher et al., 2016). The QUALIDEM tool is openly available free of charge, along with the user guide, *QUALIDEM: development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure*. No formal training is required for the use of this tool, but definitions of items are explained in the tool guidelines (Dichter et al., 2016).

The ratings are based on observations of the individual made over a two-week period, during different times of the day. The tool takes approximately ten minutes to complete. In addition to the original Dutch version, English and German linguistic-validated versions are available. Observations should be made by nursing staff and where possible the individual's key nurse is preferred. The observation of the resident can be made by one or several nurses which will increase reliability and validity of the responses given. The QUALIDEM is reported to have good inter-rater reliability (IRR) of 0.75 and above, (Ettema et al., 2007). The IRR in QUALIDEM was based on ratings by two certified nursing assistants (Ettema et al., 2007). The nursing assistants observed the same resident independently from each other over a two week period. The authors recommended totaling the component sub-scales separately (Dichter et al., 2016). The authors argue that totaling all scores could result in valuable information being lost, but state that if necessary a total score can be calculated for statistical analysis (Dichter et al., 2016).

Face validity of QUALIDEM was reported during the development of the measure through a focus group being held with people living with dementia (PLWD) and professional panels, including nurses, psychologists and physicians working in care homes (Ettema et al., 2007). Convergent and discriminatory validity of the QUALIDEM are reported using the one-method multi-trait matrix which resulted in a majority of correlations (90.5%) in support of either convergent or discriminant validity (Ettema et al., 2007).

AwareCare

The AwareCare tool (Clare et al., 2012) is an observational measure that has been developed to aid staff training, support everyday practice and identify signs of awareness of residents living with advanced dementia. This is important as more people are progressing into the later stages in dementia and in need of care provision (Clare et al., 2012). Individuals living with advanced dementia can be at risk of being overlooked, and in some environments for example, sensory-overload can increase withdrawal symptoms. Despite this, some environments may be lacking in meaningful activity, contributing to decline (Margallo-Lana et al., 2001). Lack of stimulation and meaningful activity can occur in situations where staff may assume that individuals lack awareness and responsiveness and staff may be less likely to engage with those individuals (Clare et al., 2014; Magai et al., 1996). Consequently, presumptions of lack of awareness for those who are viewed as less responsive mean they receive least interaction which can have powerful implications for residents' quality of life and well-being (Clare et al., 2012). The AwareCare tool allows staff to observe subtle signs of awareness and responsiveness to naturally occurring observable environmental stimuli, which can be implemented in everyday practice (Clare et al., 2012).

To complete the AwareCare observational measure, observations are made by trained staff members for at least 10 minutes, over a number of occasions at different times of day, in communal areas of the home. The measure lists 10 events. Seven of these might occur spontaneously in the environment during the observation period (e.g. resident is touched, there is a loud noise, food or drink is offered), whereas three are designed to be introduced by the observer (e.g. resident is called by name, or the observer takes his/her hand). For each event that is observed, the response of the person with dementia is noted, using six groups of responses (14 in total) relating to: eyes (e.g. explores with eyes), face (e.g. smiles), head (e.g. moves head), arm (e.g. grasps or holds), body (e.g. moves away) and sounds (e.g. mumbling). An AwareCare responsiveness index (AwareCare RI) has been developed (Clare et al., 2014), which for each resident is the number of responses made by the resident divided by the number of occurrences of events during the observation period. A higher RI indicates greater responsiveness.

In an intervention study, staff were trained in the use of the measure, and the AwareCare authors refer to the training being led by an accredited trainer (Clare et al., 2012). AwareCare trainees were encouraged to consider the nature of the resident's awareness during the use of the measure and provided with guidance on developing their communication skills with individuals, who had severe impairment. Staff using the tool in the intervention study practiced over two sessions before being assigned their individual residents to observe over a number of weeks and attended a fortnightly group supervision session. The tool is available to access (http://reach.bangor.ac.uk/AwareCare.pdf) with user information and guidelines.

Several psychometric properties are recorded for the AwareCare tool. Inter-rater reliability was good, in relation to whether an event occurred or not within a time period (mean Cohen's Kappa 0.75 for the spontaneously occurring events). In addition, there was generally good agreement as to whether a response occurred, with interrater reliability consistently high (mean > 0.6) for most of the response categories, Test-retest reliability was investigated, observing participants on two occasions, and looking at how many times a particular stimulus elicited the same response in both observation periods. Results found considerable variability across both time points, and in which stimulus elicited the same response and the authors do not report a Cohen's Kappa value. They do report the stimulus "someone nearby" was the most likely to elicit the same response while “loud noise” was the least likely to elicit the same response. Clare et al. (2012) further explain the difficulties of measuring test-retest reliability in naturalistic settings where variability is expected as participants’ responses can be influenced by various factors beyond researcher control, which would be true of all measures, factors such as internal (fatigue, pain), environmental (e.g., activity, noise) and contextual (e.g., the nature of the environment immediately prior to observation) (Clare et al., 2008; Clare et al., 2012).

Face validity was addressed by including families, family caregivers and care professionals alongside researchers in the development of the instrument through discussions of indicators of awareness of people living with advanced dementia and applicability of items. Concurrent validity was examined in terms of the measure’s association with The Positive Response Scale (PRS; Perrin, 1997) and staff ratings of QoL using the QUALID (Clare et al., 2013). Evidence of concurrent validity was provided by a positive correlation with PRS score, indicating that participants who scored more positive responses on the PRS also showed greater responsiveness on the AwareCare. Further evidence of concurrent validity was found by Clare et al. (2013), with staff ratings of QUALID correlating with responsiveness on AwareCare.

It was found that staff were able to carry out the AwareCare measure effectively and relatives of residents reported an improvement of QoL (Clare et al., 2012), following communication training based on the tool. Staff also felt that they benefited from the training as they gained a greater understanding of residents’ behaviour and responsiveness (Clare et al., 2012). Enabling the staff to understand signs of awareness and responsiveness supports staff in meeting residents’ needs and encourage responses, contributing to their well-being.

Measures of Health related QoL (HRQOL)

The three measures for HRQOL found in the search, QOL-D, ADQRL and QUALID, all include positive and negative aspects of HRQOL, encompassing enjoyment of activities, social interaction and positive mood as well as negative affect and distress. These measures have been developed to evaluate the outcomes of behavioural, pharmacological and environmental interventions.

QOL-D

The QOL-D was developed in Japan (Terada et al., 2002). Items are derived from subjective and objective measurement of social, psychological, and physical domains. The measure consists of 31 items grouped into six domains, each with its own scale. Items are rated using a response-scale, ranging from ‘none’ (1) to ‘frequent’ (4). The six domains are: positive affect, ability to communicate, negative affect and actions, spontaneity and activity, restlessness, and attachment to others. Higher scores indicate higher QoL with the exception of negative affect and actions and restlessness, where higher scores would indicate lower QoL. Two versions of the instrument exist: a caregiver version, which is completed by a proxy and rates both activity and affect; and a resident version, which is completed by the person with dementia (Bowling et al., 2014). No training is required for this measure; however, evaluators must have good knowledge of the individual (Terada et al., 2013). This measure is sometimes known as the Activity and Affect Quality of Life. Additionally, a shorter version of the QoL-D is available (short QoL-D) consisting of 22 items, requiring less administration time. The shorter version of QoL-D correlated highly with the original version (Terada et al., 2013).

The QOL-D shows moderate to very good agreement between proxy raters (Terada et al., 2002). The IRR was assessed using the intraclass correlation coefficient (ICC). The range of ICC’s as reported by four individual evaluators, for total scores across six summary scales, was 0.63 to 0.90 (Terada et al., 2002). Face validity of this measure was demonstrated during its development through a comprehensive review of the literature and of existing measures, collating information obtained from interviews with family carers and care staff, expert opinion and selecting domains considered important to professional caregivers (Terada et al., 2002). Construct validity is reported, with the total scores in four of the domains (positive affect, ability to communicate, spontaneity and activity, and attachment to others) having moderate to strong positive correlations with total scores on the Nishimura mental state scale (NM scale) and Nishimura Activities of Daily Living scale (N-ADL scale) (Nishimura et al., 1993). In contrast, the other two domains, restlessness and negative affect and actions, had weak or no correlation with the degree of dementia. This implies the frequency of positive affect, communication ability, spontaneity and activity, and attachment to others decreased as dementia progressed. However, negative affect and actions showed no relationship with cognitive impairment or ADL function. Restlessness showed a weak correlation with cognitive and ADL function. Interestingly, there was no relationship between positive and negative affect, even when controlling for cognitive impairment.

ADQRL

The ADQRL was based on Lawton's (1994) model of HRQOL in dementia and developed to measure multifaceted domains of QoL (Kasper, Black, Shaw & Rabins, 2009). The development of the ADQRL relied on experts (health professionals and the authors) to form domains and a focus group of family carers of PLWD. An assumption was made by the developers that PLWD were unable to give their own views on their QoL, a common view at the time, although now recognised as invalid (Kasper et al., 2009).

The ADQRL was designed for use by both formal and family caregivers, focusing on observations made regarding the day-to-day lived experiences of the individual over the previous two weeks. An advantage of the ADQRL is that it can be implemented at home and has been successfully applied in assisted living and care home settings. Furthermore, the ADQRL is said to be sensitive to change, which allows researchers to evaluate the impact of the environment on individuals' well-being by comparing aspects of QoL between an individual's home environment and a care home placement (Kasper et al., 2009) and can be used as an outcome measure. The majority of questionnaire items (originally 47, but reduced to 40 by Kasper et al., 2009) are based on observable behaviours that occur. The items are grouped into 5 domains including positive and negative factors: Social interaction, Awareness of self, Feelings and mood, Enjoyment of activities and Response to surroundings. Each domain contains from 5 to 15 items, which are scored as 'agreed' or 'disagreed'. Individual items are assigned weights, ranging from 9.15 to 13.51, which aim to reflect the extent to which the item influences quality of life. A summary of scores is generated for each domain and for global quality of life; each is computed so as to range from 0 (lowest quality) to 100 (highest quality) (Sloane et al., 2005).

The internal consistency reliability for the total revised ADQRL scores as reported in the evaluation carried out by Kasper et al. (2009) was 0.86, with subscale reliability coefficients ranging from 0.56 (Response to surroundings) to 0.83 (Social interaction). Item internal consistency coefficients – the extent to which individual items correlated with their designated sub-scales - ranged from .23 to .68. Overall, 67.5% of items (27/40) met the .40 standard for supporting item-internal consistency. The construct validity of the ADQRL is supported by its ability to discriminate based on cognitive and physical functioning. Those who experienced a decline in Activities of Daily Living scale (ADL) over a 12-month period also experienced a decline on ADQRL scores (Kasper et al., 2009). The measure is available in English and has also been translated in Japanese. The ADQRL is only available through contact with the original author. No formal training is required for its use but users are recommended to watch a free training video.

The Quality of Life in Late-Stage Dementia Scale (QUALID)

The QUALID (Weiner et al., 2000) is also based on Lawton's (1994) four component division of QoL in dementia into objective criteria (behavioural competence and aspects of external environment) and subjective criteria (perceived QoL and psychological well-being). QUALID was developed from Albert et al.'s (1996) affect and activity measures, suitable for individuals living with advanced dementia in care home settings. QUALID is completed by family members or professional caregivers, based on the person's mood and behaviour over the preceding seven days. The QUALID includes 11 items of positive and negative components of observable mood and behaviour considered indicative of QoL in advanced dementia. Scores are rated from 1 to 5, with *lower* scores indicating a higher QoL (Castro-Monteirio et al., 2016). Individuals in the later stages of the illness express everyday behaviours (smiles, laughs, sadness, cries, discomfort, irritability, calmness), and behavioural signs of comfort and participation in basic activities (eating, touch and interacting with others). The measure focuses on basic activities to minimise the confounding effects of cognitive impairment.

Weiner et al. (2000) provide preliminary information on the psychometric properties of the QUALID. Inter-rater reliability was estimated for 23 people with dementia evaluated by two raters based on reports from each of two members of nursing staff who had spent at least 30 hours with the resident in the previous week. The mean ICC was very high (0.83). For test-retest reliability, the QUALID was administered twice over a 2-3 day period for 19 residents. There was a high test-retest reliability (ICC = 0.81), with very little difference in scores between the two assessments (Weiner et al., 2000). In the same study, internal consistency was also high (0.77), evaluated on 31 completed assessments. In terms of construct validity, QUALID scores were measured by Weiner et al. (2000) alongside scores from Mini-mental state examination (Folstein, Robins & Helzer, 1983; MMSE), Physical Self-Maintenance Scale (Hayslip & Panek, 1983; PSMS), Geriatric Depression Scale (GDS) and Neuro Psychiatric Inventory (NPI). No significant correlation was found for cognitive function (MMSE) or self-care ability (PSMS), but there were significant correlations between the QUALID and depression (GDS) and neuropsychiatric symptoms (NPI).

More recently, Clare et al. (2014) report further details of the psychometric properties of the QUALID, in larger samples, with ratings made (separately) by both care home staff and residents' relatives. The difference in severity of cognitive impairment in the samples included by Clare et al. and by Weiner et al. should be noted; the mean MMSE score in the Weiner et al. study was 11.53, whereas all the residents in the Clare et al. sample were too impaired to score at all on such a test. Clare et al. report good internal consistencies for proxy ratings by both staff (n=105; Cronbach's alpha=0.67) and family members (n=73: Cronbach's alpha=0.70). Care staff ratings were related to a rating of the person's mood (on the BASOLL scale: Brooker et al., 1998), benzodiazepine use and the responsiveness index of the Awarecare tool (Clare et al., 2012). In contrast, proxy ratings by family members were related only to use of antipsychotic medication. Whereas Weiner et al. (2000) reported that principal component analysis identified a single factor underlying the 11 items, in their larger and more impaired sample Clare et al. found evidence for two distinct factors, which were essentially the same for staff and family ratings. These reflected discomfort/distress and sociability respectively.

Evidence is available to suggest that the QUALID is sensitive to change in relation to both pharmacological and non-pharmacological interventions and therefore has the potential of being used as an outcome measure (Clare et al., 2013; Garre-Olmo et al., 2010; Martin-Cook et al., 2005). In the Clare et al. (2013) study, ratings made by family members showed improvement in QUALID scores, whereas those by staff did not, in response to a staff training intervention. The measure includes a rating for the overall quality of the responses, which includes the raters' understanding of the items/responses and their knowledge of the individual living with dementia. These additional scores are not included within the total score, but provide information about the validity and reliability of the ratings. The QUALID can be implemented easily by care staff, with no formal training required and can be used as an information resource for care staff, which could add to staff knowledge about individual residents and what contributes to their QoL (Weiner et al., 2000). The QUALID is readily available online (although this was not reported in the paper). The QUALID is available to freely download online at: (https://www.toronto.ca/legdocs/mmis/2009/ha/bgrd/backgroundfile-24240.pdf).

Quality evaluation

Table 2.2 provides an itemised overview of the consensus ratings for the developmental measurement properties and functionality of the six identified measures. More details regarding the rating of each criterion are provided by Francis et al. (2016). Findings for each domain are summarized below.

Conceptual model

A clear statement of the conceptual model is helpful in the process to provide the intended audience with a rationale and description of the concept it intends to assess and provide understanding of the usefulness of the measure for their purposes. This information was included by all measures apart from ADQRL and QUALID. All measures made clear their intended respondent population. For DCM and Awarecare it was unclear whether the conceptual model would lead to a single scale or multiple sub-scales.

Content Validity

All measures gave evidence of experts being involved in the development of the measures and provide clear evidence of the methodology by which the items were determined for inclusion. The DCM and QUALID did not report the direct involvement of the respondent population (respondents in this case being those making the ratings, rather than the people with advanced dementia) in the development of the tools.

Reliability

All measures tested reliability and were found to have adequate indices ($r \geq 0.70$). Internal consistency was reported by ADQRL, DCM, QUALID, QOL-D and QUALIDEM.

Table 2. 2. Developmental characteristics and applicability of selected measures (Francis et al., 2016)

The score column indicates for each measure whether or not the information provided in the source documents meets each of the criteria (0=criterion not met, 1=criterion met). 'PRO' refers to 'Patient-Reported Outcome'

	Conceptual Model	**ADQRL**	**Awarecare**	**DCM**	**QUOL-D**	**QUALID**	**QUALIDEM**
1	Has the PRO construct to be measured been specifically defined?	**0**	**1**	**1**	**1**	**0**	**1**
2	Has the intended respondent population been described?	**1**	**1**	**1**	**1**	**1**	**1**
3	Does the conceptual model address whether a single construct / scale or multiple subscales are expected?	**1**	**0**	**0**	**1**	**1**	**1**
	Content validity						
4	Is there evidence that members of the intended respondent population were involved in the PRO measure's development?	**1**	**1**	**0**	**1**	**0**	**1**
5	Is there evidence that content experts were involved in the PRO measure's development?	**1**	**1**	**1**	**1**	**1**	**1**
6	Is there a description of the methodology by which items/questionnaires were determined (e.g. focus groups, interviews)?	**1**	**1**	**1**	**1**	**1**	**1**
	Reliability						
7	Is there evidence that the PRO measure's reliability was tested (e.g. test-retest, internal consistency)?	**1**	**1**	**1**	**1**	**1**	**1**
8	Are reported indices of reliability adequate (e.g. ideal, r> 0.80; adequate: r >0.70; or otherwise justified)?	**1**	**1**	**1**	**1**	**1**	**1**
	Construct Validity						
9	Is there reported quantitative justification that single scale or multiple subscales exist in the PRO measure (E.g. factor analysis, item response theory)?	**0**	**0**	**0**	**1**	**1**	**1**

10	Are there findings supporting expected associations with existing PRO measures or with other relevant data?	**0**	**1**	**1**	**1**	**1**	**0**
11	Are there findings supporting expected differences in scores between relevant known groups?	**1**	**1**	**1**	**0**	**1**	**0**
12	Is the PRO measure intended to measure change over time? If YES, is there evidence of both test-retest reliability AND responsiveness to change? Otherwise, award 1 point if there is an explicit statement that the PRO measure is NOT intended to measure change over time	**1**	**1**	**1**	**0**	**1**	**1**
	Scoring & Interpretation						
13	Is there documentation how to score the PRO measure (e.g. scoring method such as summing or an algorithm)?	**1**	**1**	**1**	**1**	**1**	**1**
14	Has a plan for managing and/or interpreting missing responses been described (i.e. how to score incomplete surveys)?	**0**	**0**	**0**	**0**	**0**	**1**
15	Is information provided about how to interpret the PRO scores [e.g. scaling/anchors, (what high and low scores represent), normative data, and/or description of severity (mild -> severe)]?	**1**	**1**	**1**	**1**	**1**	**1**
	Respondent burden & presentation						
16	Is the time to complete reported and reasonable? OR, if it is NOT reported, is the number of questions appropriate for the intended application	**1**	**1**	**0**	**0**	**1**	**1**
17	Is there a description of the literacy level of the PRO measure??	**0**	**0**	**0**	**0**	**0**	**0**
18	Is the entire PRO measure available for public viewing (e.g. published with the citation, or information provided about how to access a copy?)	**0**	**1**	**0**	**0**	**0**	**1**

Construct validity

More gaps are evident in the reporting of construct validity than in other domains. A justification for scales or subscales is provided by QOL-D, QUALID and QUALIDEM. The measures AwareCare, DCM, QOL-D and QUALID gave evidence of findings which supported associations with other relevant measures that would be predicted to correlate with QoL; this evidence was not provided by ADQRL or QUALIDEM. All measures except QOL-D showed sensitivity to change.

Scoring & Interpretation

All measures provided documentation on how to score items. Measures did not do well in providing information for interpretation of and dealing with missing data, only demonstrated in QUALIDEM. Providing a plan for dealing with missing responses is crucial for consideration in observational studies, as it is expected the main respondents will be family members and professional caregivers and it is likely that they may be unable to provide complete data due to the nature of their role.

Respondent burden & presentation

Information regarding the time required to complete a measure is fundamental for researchers when considering measures in this area. As the main respondents are likely to be family members and professional caregivers, the time to complete should be reasonable, minimising fatigue on participants. The DCM has been reported as requiring between one to six hours to complete the observations; the authors have acknowledged that the observation window is time intensive. The time required would not generally be considered feasible or practical for use by care staff during their working day. Information regarding time to complete is not reported in QOL-D, whilst the remaining measures report a time between 5-10 minutes to complete. None of the measures report details of the literacy levels required, and only Awarecare and QUALIDEM are reported as readily accessible in full for use and evaluation, although the QUALID is also readily available.

Discussion

This review aimed to add to the knowledge of the availability, applicability and suitability of QoL measures in advanced dementia. This review provides information on the use of QoL measures which are applicable to people living with advanced dementia, which are also suitable for care home settings, which is most likely to be a requirement when selecting measures for use in the later stages of the illness.

The review identified six measures available for measuring QoL in the advanced stages of dementia. All measures were appropriate for use in care home settings, however they may not all be accessible for use. The majority of the identified measures met most of the quality criteria set by Francis et al. (2016). However, some measures fell short on the scoring criteria when defining the concept of QoL and in providing information regarding construct validity.

Family and professional caregivers and PLWD opinions were sought during the development of the DCM, QUALIDEM and AwareCare measures. The authors of QOL-D report family caregivers and professional opinion in their design, QUALID and ADQRL discuss development with professionals only. This is an important consideration when choosing and evaluating the content validity of QoL measures for PLWD. The DCM, AwareCare and QUALIDEM, QUALID and ADQRL have indicated sensitivity to change; the DCM, AwareCare and QUALIDEM have also been used to aid staff development. Both AwareCare and QUALID authors report their potential as outcome measures which is likely to be of value as more interventions become available for people living with advanced dementia.

Of the six instruments, AwareCare, QUALIDEM and QUALID are easily accessible with no formal training required and no set hours of observation time. The DCM requires formal training for mappers and the observation period is time extensive, which could discourage the use of the tool. No training specifications have been indicated for the QOL-D, and ADQRL recommends users to watch a free training video. Although the use of the DCM is free, it does require users to attend a four-day training course, which has associated costs. With regards to QOL-D and ADQRL, as these instruments require the measures being obtained from the original authors, they may not be feasible or readily accessible for use. In terms of assessment, AwareCare and DCM require ‘in the moment’ observations, whilst the remaining instruments assess QoL over a period of 1 to 2 weeks.

Research regarding the QoL of people living with advanced dementia is limited. There may be many reasons for this however, the majority of instruments screened for this review were only suitable for people in the earlier stages of the illness, as was the case in the review carried out by Bowling et al. (2015). This could, in part, contribute to the lack of research in this area, with the limited measures available coupled with difficulty accessing some applicable measures. Despite this, understanding different aspects of QoL for people at the later stages of the illness, where they are likely to have limited verbal communication, is important in order to establish the factors contributing to QoL. As mentioned by Clare et al. (2012) measuring QoL in care practice provides the opportunity to make changes within the environment and increase staff knowledge of the resident's responsiveness and awareness.

Measuring QoL as part of care practice for PLWAD could establish benefits for both PLWAD and those providing care. It might be assumed that measures investigating QoL would be person-centred. However, a challenge arises when trying to evaluate the QoL of a unique individual. Existing measures are underpinned by standardised frameworks and models of QoL incorporating items which may differ from the individual's QoL, with a focus on health status, rather than QoL of the individual. It could be argued that standardised measures are tailored towards what health professionals and clinicians deem as QoL, or what society believes to represent QoL for an individual who is living with an illness and are in fact of little meaning for those individuals. This is reflected in the development of measures that did not include consultation with PLWD; QOL-D, ADQRL and QUALID did not consult with individuals living with dementia. Of course, there are shared aspects of QoL, but the significance of those factors will differ between individuals. With this in mind, when it comes to reporting QoL of individuals, it is not unreasonable to assume variations in what the person expects from QoL and that this will impact on measuring QoL (Bowling et al., 2014). Therefore, employing standardised measures may not capture a person's QoL, and if measures are not capturing accurately elements that contribute to QoL, they may be unlikely to show improvements, as a result of not having measured elements important to the individual or the particular group being evaluated (Edelman et al., 2005).

Employing a disease specific assessment will consider the problems which may arise as a result of the illness, which perhaps improves the likelihood of response to change (Edelman et al., 2005). However, a disadvantage of disease-specific measures is that they do not allow for the opportunity to compare QoL across co-morbid conditions or other health and non-health related conditions, as the instruments may differ in their conceptual approach (Schiffczyk et al., 2010). Although dementia-specific measures may be preferred when evaluating QoL in dementia, this does not come without complexities of its own, coupling conceptualizations and methods e.g. health related versus multidimensional QoL (Bowling et al., 2014).

Among generic measures, the EQ-5D was designed for evaluating HRQoL, and has been employed in the study of people living with mild to advanced stages of dementia (Devine et al., 2014). Both self-report and proxy (EQ-5D-P) versions are available. The instrument is based on a descriptive system that defines health in five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has a level ranging from one (no problems) to five (severe problems) followed by a Visual Analogue Scale (VAS) of a participant's overall health state. The domain responses are calculated into utilities (index scores). The EQ-5D has been widely used in the evaluation of healthcare interventions and has shown high reliability, responsiveness, validity, and short completion time (Brooks, 2013). Furthermore, the EQ-5D has been used as an outcome measure, for several clinical trials and interventions in dementia research (e.g. Orgeta et al., 2015), but concerns have been raised regarding the validity of the proxy EQ-5D-P (Hounsome, Orrell & Edwards, 2010), which has also been a criticism of many other proxy measures (Clare et al., 2014; Jin et al., 2011; O'Shea et al., 2018). Nevertheless, the measure is accessible and provides the opportunity for comparisons across other illnesses and an effective means of comparing the impact of illness on groups of individuals (Hounsome, Orrell & Edwards, 2011). Recently, a direct comparison of the EQ-5D and QUALID in a longitudinal context has been reported by Sopina et al (2019). Their conclusion is clear: the QUALID is the preferred measure in advanced dementia, as the EQ-5D does not capture aspects of HRQoL relevant to people with advanced dementia.

Domains important to QoL at different stages are important to consider in terms of measures. At later stages comfort and safety may be considered of primary importance over items such as 'going to the shop' or 'keeping in touch with others', which are included in measures for mild to moderate stages such as the dementia quality of life measure (DEMQOL; Smith et al., 2005). At first sight, tools such as DEMQOL-proxy appear to hold promise for measuring QoL throughout the dementia journey, including in advanced dementia. However, when the DEMQOL-proxy was evaluated, carers commented the questionnaire was too long and several items could not be completed as they were not suitable such as 'looks after his/her finances' (Smith et al., 2005). Employing a measure which is unsuited for the later stages of dementia could limit responses, and negatively skew the view of the individual's QoL. Furthermore, a measure designed for earlier stages of dementia could divert raters to respond negatively, associating the items with the sense of loss and placing focus on activities that the individual is no longer able to participate in instead of what they are still able to enjoy. More research is needed to distinguish the differences in QoL between the different stages of dementia (Jin et al., 2016). Consequently, the majority of measures are unable to assess QoL fluidly throughout the dementia journey which then makes it difficult to measure QoL across time and evaluation of interventions as changes will be difficult to assess across instruments and across time (Ettema et al., 2005).

There is no gold standard in measuring QoL on behalf of individuals as there are confounding variables, such as proxy-bias and factors considered or not considered in the particular instrument. The chosen method will depend on the population under study, as different tools will be needed to tailor for individuals in different stages. Therefore, measures need to account for factors which are important to individuals at different stages and factors that remain throughout the dementia journey. This is important to consider when employing a measure as these factors will influence evaluator's ratings. The authors of QUALID (Weiner et al., 2000) discussed the inclusion of basic QoL elements (smiling, crying, calmness, distress) and activity (eating, interacting with others), focusing on basic domains to minimise the confounding effects of cognitive impairment (Weiner et al., 2000). Authors of the AwareCare tool discuss the development of the tool, referring to behaviours staff can identify. The AwareCare tool respondents are asked to record behaviour such as 'moves forward' 'makes eye contact'. Staff have to respond to perceptual awareness, for people at the later stages of the illness, who may have limited verbal ability, their ability to respond to stimuli whether internal states or environmental features is embodied in behavioural responses. The demonstration of awareness and responsiveness being, at least in some part, affected by the environment which this tool also highlights, reflects the importance of creating an appropriate environment (Clare et al., 2013). Having care staff document these subtle, yet observable behaviours in the naturally occurring environment increases their awareness of the resident's responsiveness. Similarly, DCM has been reported to support staff understanding of the perspective of the PLWD and increase person centered care, with care staff reporting feeling more connected with PLWD, improvement in interactions and delivery of person-centred care (Surr et al., 2016).

Recommending one measure from this review as the most applicable is not feasible, but it is argued that there are many factors to consider, such as psychometric properties and time taken to complete evaluations. We have discussed measurements' psychometric properties, training requirements and accessibility, identifying both strengths and weaknesses in all measures. Furthermore, when considering measures as part of care practices, feasibility, accessibility and time to complete evaluations are important considerations. It is likely that staff will have less time to complete evaluations, therefore instruments and guidance need to be accessible and able to be followed with ease. Practical considerations need considering, for example the DCM requires continued observation for up to 6 hours. Of all the measures identified in this review the AwareCare and QUALID provide information on all aspects of validity and reliability. The DCM was the most established measure found, with a wealth of data and has been shown to be sensitive to change and has the advantage of up to eight persons being evaluated at one time. However, the DCM was the most labour intensive, requiring a four-day training course and hours of observation. The QUALIDEM is accessible, free of charge and also provides guidance regarding administration and scoring. The QUALIDEM is available in Dutch and German validated versions, but the English version, although available, is yet to be validated. A growing body of evidence for the QUALID is available, but some queries regarding its factor structure remain. However, the measure does have an advantage of being brief and easily implemented and accessible. Both ADQRL and QOL-D are difficult to access and there is limited information available. Both measures do not require formal training and the QOL-D has a shorter version available.

Another factor to consider is how QoL is evaluated in the later stages of dementia, where proxy-measures are often employed. Proxy methods allow people in the advanced stages to partake in research as they may be unable to navigate other measures (Algar et al., 2016). Often proxy measures are undertaken by a family member or professional caregiver on behalf of the individual. However, measuring QoL by proxy does not come without limitations. Studies comparing evaluations made by PLWD and proxies found discrepancies in ratings of QoL as proxy ratings are lower than that of the PLWD (Clare et al., 2014; Buckley et al., 2012; Hoe et al., 2007; O’Shea et al., 2018). Conflicted ratings are not exclusive to raters and individuals with dementia. Research findings (Bosboom et al., 2012; Sands et al., 2004; Schiffczyk et al., 2010) have identified significant differences between professional care staff and family raters. Family carer ratings are influenced by caregiver burden, depression and stress as well as relationship to PLWD (Buckley et al., 2012), relationship quality (Clare et al., 2014), personal health status and QoL. Family carers may project their assessment of their own QoL and health state onto their assessment of the person with dementia (Zhao et al., 2012). Larger discrepancies have also been reported in ratings of QoL, based on the relationship of the rater to the PLWD; lower proxy ratings were given by adult children carers than by spousal caregivers (Novella et al., 2001). However, studies have found self-reports of QoL to remain consistent over time, suggesting adaptation, whilst family carers' proxy-ratings decline over time with the natural progression of the illness (Bosboom et al., 2013). Due to the progression of the illness, changes will occur in cognitive and physical ability, and it is often assumed level of QoL will decline with these changes. Despite this, studies have found this may not be the case (Beerens et al., 2016).

Despite employing instruments with appropriate content for the stage of dementia, proxy bias exists, it has been known raters make evaluations based on their own feelings regarding the illness. One way of addressing this, is to ask raters to make the evaluations as if they were the individual living with dementia, rather than giving their direct opinion of their QoL (Pickard & Knight, 2005). Alternatively, employing observational measures reduces rater bias, as it gives the opportunity to represent the person's real-life experiences (Algar et al., 2016). Making direct observations of behaviours has an advantage as they are 'objective' in a sense that they are based on predefined behaviours and regularly rated over a period of time (Logsdon et al., 2002). However, observation measures do not come without limitations either, as it may be questioned how raters can determine whether what they have documented of the person's behaviour is what the individual would consider important for their QoL.

Further, instruments such as QUALIDEM, QUALID, ADQRL & QOL-D have an observation window of 1 to 2 weeks, which could be an advantage, in terms of staff working shifts and making observations over time. However, data could be missed where staff are documenting and responding to domains retrospectively. Direct 'in the moment' observation is not immune from biases associated with proxy ratings. When rating behaviour, some raters will pick up on more subtle behaviours whereas others will not. Therefore, this emphasizes the importance of training and tests of inter-rater reliability before using direct observational measures (Logsdon et al., 2002).

Conclusion

With regards to exploring factors important to individuals living with advanced dementia, where verbal communication is limited, this could be done in observation form. As found by Clare et al. (2013), care staff were able to use the AwareCare observational tool effectively, and felt that they had benefitted from the observations, gaining understanding of residents' behaviour, responsiveness and identifying needs, which in turn, adds to the residents' well-being. Furthermore, a measure suited for advanced dementia would need to ensure accessibility, providing sufficient training aids, with items which take into consideration the lived environment of the individual. Additionally, it is important to consider measures reflecting what is hoped to be achieved, as measures may be better suited to aid healthcare practices than research outcomes and vice versa.

Whilst growing research exists on living with dementia and QoL, some specific instruments will be more useful than others. But no single measure can claim superiority, and indeed, no measure can claim to capture the entire meaning of quality of life for each individual across their dementia journey. Moreover, QoL is a subjective concept, and assessment of a person’s QoL made by proxy raters will vary for those individuals. The ideal measure would be developed with PLWD and reflect goals and priorities of persons living with advanced dementia. Research in this specific area has received very little attention or innovation in recent years. Therefore, conducting research with key stakeholders, individuals living with advanced dementia, family carers and professional caregivers, to determine which factors are important and reflective of their needs, in terms of QoL, is essential and provides an opportunity for social impacts.

Pragmatically, in the empirical studies that follow, the QUALID was selected as the main quantitative index of quality of life, in view of the promising data on its psychometric properties in a population of people with advanced dementia similar to those participating here (Clare et al., 2014), and in view of the potential for family members as well as staff to act as proxy raters. Its ease of use and accessibility were also important factors. Whilst mainly used in the second empirical study (Chapter 6), the QUALID was also used more descriptively in the case-studies reported in Chapter 5, alongside the AwareCare tool, which was used to inform observations of people with advanced dementia participating in the project.

Chapter 3: Philosophical, theoretical, methodological, and ethical perspectives underpinning the research

Introduction

In this chapter I will set out certain of the key over-arching considerations, assumptions and decisions made relating to the design and conduct of the two empirical studies reported in detail in chapters 4 and 5 (Study 1) and 6 and 7 (Study 2) respectively. Specifically, I will set out the philosophical perspective underlying the research, summarise the theoretical underpinnings and discuss the major methodological approaches taken. My aim was to ensure that whilst exploring person-centred care for people with advanced dementia, that my research was person-centred to all of the participants. Accordingly, I wanted to not only understand the quality of life and well-being of the residents, but to also gather understanding of the experiences of their family members and care staff, as one does not solely exist without the other, all are inter-connected and inter-dependent.

Of course, within this area of research there are many ethical issues to take into consideration including the participants' potential lack of mental capacity and issues arising from observation of the residents living in a care home setting, which are also discussed in greater detail during this chapter.

Philosophical perspective

The project took a constructivist ontological approach, in that reality is seen as being created by social processes, rather than being objective and independent. This approach

'offers researchers an opportunity to examine in detail the labyrinth of human experience as people live and interact within their own social worlds. It aims to understand the variety of constructions that people possess, trying to achieve some consensus of meaning, but always being alert to new explanations' (Appleton & King, 2002, p642).

Multiple realities and interpretations are possible.

In this project, the inclusion of families and care staff in the research gives multiple perspectives about not only the individual residents, but the care home functioning as a whole, and the effects of the complex system on individuals. Furthermore, as the researcher in this project, it was important that I explored and understood the wider context of the residents' now 'home'. In considering this wider context of the residents' home, I was looking at the care home and understanding each home as a complex system, which accommodates many people beyond the individual residents partaking in this project.

Rather than a positivist hypothesis-driven study, this project has focused on an in-depth understanding of the lived experiences of key stakeholders within the care homes. The aim behind this project was to explore experiences of a small number of care homes, to gather in-depth and personalised reflections, as opposed to gathering large sets of data from a larger number of care homes. The aim was therefore not to be able to generalise, but to understand the lived experience. This approach was a good fit with the initial funding for the project from a small care home group.

It is also important to acknowledge my relationship to the research and assumptions I brought to the project as the researcher. I have already outlined my previous experiences and motivations for undertaking the research in Chapter 1. The project took an interpretivist epistemological approach that acknowledges that these experiences and my interactions with participants shaped my understanding of the data. This means that the story and meaning of the data is embedded within the participants' experiences, and the meaning is mediated through the researcher's perceptions (Tubey et al., 2015). As an interpretive researcher, I sought to understand the data through 'first-hand experience, truthful reporting, and quotations of actual conversations' from stakeholders (Tubey et al., 2015 p226) in order to 'enable rich and detailed, or "thick description" of social phenomena by encouraging participants to speak freely' (Tubey et al., 2015 p226).

Theoretical perspective

Little has been explored in terms of quality of life, well-being and human rights for those individuals living with advanced dementia in care homes. The focus has been centred on earlier stages of dementia where individuals have been able to give their own views. Further, the literature reviewed in Chapter 2 also highlighted that research is limited on quality of life and its evaluation for individuals at this stage. My aim in this project was to explore how a person living with advanced dementia could maintain their quality of life, well-being, and human rights despite the possibility that they may be unable to communicate their views. I wanted to understand how person-centred care could be achieved at this stage, in a situation where a person might be unable to discuss their wishes and be an individual living in a care home environment, with many possible human rights issues to consider.

This project has drawn on two main theoretical perspectives that have rarely been brought together in this context, Kitwood's theory of person-centred care (1997) and the FREIDA principles of human rights (Curtice & Exworthy, 2010), which are both discussed in further detail in Chapter 1. At the heart of Kitwood's theory is the notion that quality of life and well-being of residents does not exist alone but is dependent on the person's social environment and care interactions (Kitwood, 1997). Accordingly, during this study the wider culture and context of the care home is considered. Whilst considering the wider care home context, this project has also explored the experiences and well-being of care staff and family members, and given recognition to these individuals as important components of the functioning of the care home, seeking to understand how all three sets of stakeholders' experiences are interwoven. In terms of the human rights approach, as Kitwood's theory suggests, the wider context of the individual's lived environment must also be considered. As dementia progresses, the individual living with advanced dementia becomes increasingly reliant on those such as care staff and relatives to uphold and promote their rights (Butchard & Kinderman, 2019). There is a clear overlap between Kitwood's theory and the principles of FREIDA, working towards the promotion of well-being of individuals living with dementia, promoting autonomy, and empowering those individuals, which is discussed in Chapter 1.

Methodological perspective

Influence of constructivism on methodology

Having now set out and made explicit my philosophical perspectives, these inevitably had a number of implications for the methods undertaken throughout this project, in terms of seeking a rich understanding of multiple perspectives and of their meanings, shaped by my perceptions and involvement as the researcher. Appleton and King (2002) helpfully indicate some of the implications of the constructivism approach generally for methodology, as shown in Table 3.1, which resonated with the studies reported in this thesis. For example, my interpretivist epistemology is reflected in the way in which personal, intuitive experience guides the research process and the researcher is flexible and responsive in engagement with the inquiry. The research design is tentative, in that it developed through the process of the research, rather than the whole programme being set out at the outset. A number of the other identified areas of methodology, including issues of access and ethics are discussed in further detail in the following sections.

Table 3. 1. The interaction between constructivism and methodology (adapted from Appleton & King, 2002).

Methodological steps	**Constructivism**
Personal intuitive experience	Informs and guides the inquiry process
Issues of rigour	Four stages for establishing trustworthiness: credibility; transferability; dependability; confirmability
Issues of ethics	Intrinsic adherence to ethical behaviour which protects privacy, confidentiality and prevents coercion
Issues of access to the natural setting	Access attained through discussion and engagement with all participant groups in the natural setting
Researcher as instrument	Able to be flexible, proactive and responsive to the demands of the inquiry process
Tentative research design	Because of the emergent nature of the inquiry
Qualitative methods	Flexible emic focused strategies such as in-depth interviews, focus groups, participant observation, documentary evidence are used
Purposive sampling	Identification of key informants who are prepared to share their constructions of the phenomena
Inductive analysis	Constant comparative analysis during and following data collection – unitizing, categorizing and pattern building
Hermeneutic–dialectic approach	Seeking clarification of consensual and divergent thinking
Interpretation of findings	Achieved through extensive familiarity and consideration of the study data
Presentation of findings to other similar groups	Results can be presented to groups of individuals in similar contextual situations as part of research process

Mixed Methods

Although as indicated in Table 3.1, a constructivist approach is typically associated with qualitative methods, a mixed methods approach is employed in the studies presented in this thesis. An intention to use a mixed methods approach was drawn, in part, from the original funding proposal interested in exploring methods of measuring quality of life in people living with advanced dementia, whilst recognising the importance of multiple perspectives. The mixed methods approach used here was intended to add to the understanding of the experiences of stakeholders and the meanings of those experiences, by adding an extra dimension to the qualitative findings, and enabling a fuller description of the stakeholders and their perspectives.

Mixed methods approaches draw upon the strengths of both quantitative and qualitative approaches and provide an innovative approach for identifying issues in health services. The integration of quantitative and qualitative data can significantly enhance the value of the research (Bryman 2006; Creswell and PlanoClark 2011), with several advantages from integrating the two forms of data. The qualitative data can be used to assess the validity of quantitative findings. The quantitative data can also be used to help explain findings from the qualitative data. Qualitative inquiry can inform the development or refinement of the quantitative instruments or interventions and generate hypotheses in the qualitative element for testing in the quantitative element (O'Cathain, Murphy, and Nicholl 2010).

The mixed method approach adopted for this research is slightly different between the two studies. In Study 1, the perspectives of relatives and staff are explored using qualitative data only, whereas both quantitative (rating scales and structured observations) and qualitative methods (interviews and field notes) are used to understand residents' perspectives. These are brought together at the analysis stage (O'Cathain et al., 2010) in a case study framework merging all the available data (Fetters et al., 2013).

In Study 2, where resident perspectives were not sought directly, the mixed method approach used for data from staff and relatives could be described as again being conducted within a case study framework (Fetters et al., 2013), where 'both qualitative and quantitative data are collected to build a comprehensive understanding of a case, the focus of the study' (Fetters et al., p. 2138). In this study, a convergent, parallel mixed methods design was used (Fetters et al. (2013). Quantitative data (questionnaires and rating scales) and qualitative data (interviews with staff and relatives) were analysed and first reported separately, before being brought together at the interpretation stage, for 'triangulation', defined by O'Cathain et al., 2010 (p.1147) as 'a process of studying a problem using different methods to gain a more complete picture'.

The aim of using a mixed method approach was to provide an in-depth reflection of participants' experiences. Whilst qualitative methods allow for more person-centred and richer accounts and reflections from participants during interviews, quantitative data, used to describe and explore, potentially adds a further dimension. The aim of using quantitative methods is to provide additional support to the qualitative data collected and to explore in practice certain of the measurement tools that appeared useful from Chapter 2 of this thesis. For example, in Chapter 6, demographic and questionnaire data are presented and analysed, in order to provide a detailed description of each of the care homes, the residents, relatives and staff. For example, the use of a standardised tool such as the Clinical Dementia Rating provides evidence of the severity of dementia-related impairment in the two homes, rather than relying on the researcher's impression. Similarly, standardised scales evaluating relatives' burden and staff well-being allow comparison with broader populations as well as providing evidence for any differences between the homes in these aspects. The quantitative data also assist in understanding factors potentially associated with well-being and satisfaction of relatives and staff. The qualitative data analysis is then presented in Chapter 7, analysed using Stake's (2005) collective case study cross-case analysis approach, building on the quantitative data for a fuller and richer understanding of each case.

Stake's instrumental collective case study approach

The decision to explicitly adopt Stake's (1995) instrumental collective case study approach for Study 2 was made following consultation with an expert in qualitative methodology, with the aim of elaborating on the understanding of the issues presented in Study 1. In Study 1, the perspectives of the residents were presented as two case-studies. presenting 'Graham' and 'Martha' as individuals, where their QoL as individuals is the main subject of interest. However, interview data from staff and relatives in the two included care homes were analysed and reported together. It was important as the researcher that I could expand on the results of Study 1 of this project and there was a desire to go deeper and gain a richer understanding of the issues involved. With this in mind, I wanted to further understand the experiences of the families and care staff alongside the residents. Accordingly, a decision was made to treat each of the two homes in Study 2 as an individual case, with the perspectives of the staff and relatives embedded. The diagram presented as Figure 3.1 below represents the process of Studies 1 & 2, as the project progressed; Study 2 was specifically designed as an instrumental collective case study.

Having explored other theoretical perspectives (e.g. that of Yin, 2009), Stake's case study approach (1995) felt appropriate in expanding on the work completed in Study 1 to deepen understanding of the participants' lived experiences. The case study approach is well established and is known to give a voice to those whose experiences have not been well understood and successfully used with people living with dementia, including with those in primary care settings (Keady et al., 2004).

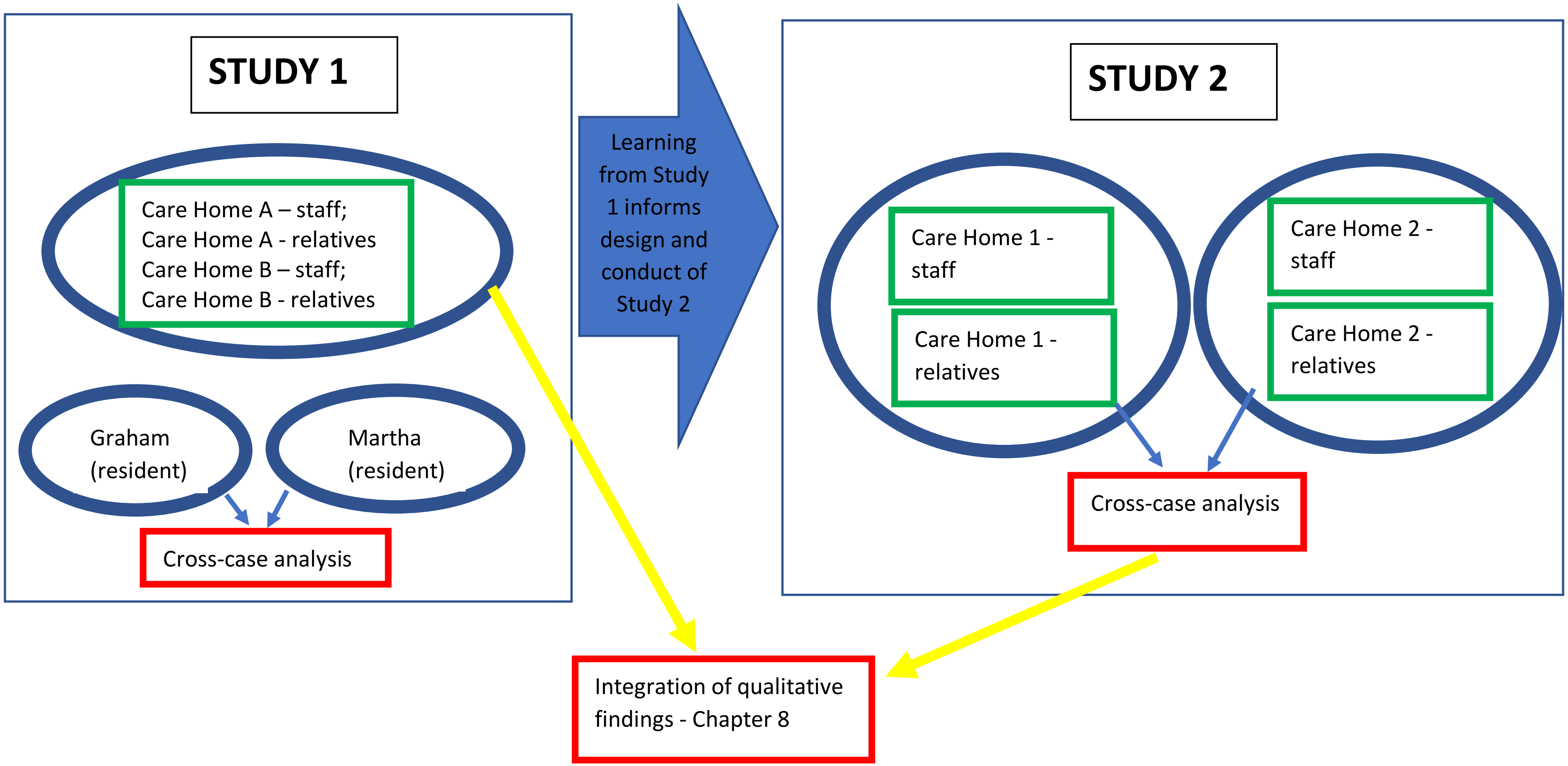
Whereas an intrinsic case study is aimed primarily at understanding the specific case, which is of interest in itself, an instrumental case study usually has one or more research questions, in addition to "What is happening?". Stake (1995; 2011) referred to these research questions as "issues." However, they consist of more than 'problems', they are concepts that may not be understood, puzzlements and possibly theoretical disagreements. The issues are used to gain a better understanding of the case and are often what capture the researcher's attention (Stake, 2011). A case study can be used to study a phenomenon, a relationship, a functioning. The case is an entity, it could be a person under research, and it could be an institution under study. The study is designed to understand the case, with the aim of seeing and understanding better the issues presented (Stake, 1995). Crowe et al. (2011, p.2) state 'The collective case study involves studying multiple cases simultaneously or sequentially in an attempt to generate a still broader appreciation of a particular issue.' The research took place across two individual care homes (not included in Study 1), purposively selected to provide a wider range of experiences and contexts, to enhance our understanding of the issues involved (Stake, 2005, p.451).

According to Crowe et al. (2011, p.6): 'In collective or multiple case studies, data collection needs to be flexible enough to allow a detailed description of each individual case to be developed… before considering the emerging similarities and differences in cross-case comparisons'. Fetters et al. (2013, p.2138) state: 'Case study involves intensive and detailed qualitative and quantitative data collection about the case'. In Study 2, in line with my mixed methods approach, demographic and questionnaire data are presented and analysed, in order to provide a detailed description of each of the cases i.e. the care homes, and to assist in understanding factors associated with well-being and satisfaction of relatives and staff.

As the project progressed then, Study 2 was designed as a collective case study, involving 2 care homes, each analysed separately as an intrinsic case study before an instrumental cross-case analysis was undertaken. Having completed Study 2, reflecting on Study 1, it appeared of interest to consider the qualitative aspect of Study 1 as a further intrinsic case study, which could then be included (in the Discussion, chapter 8) in a cross-case comparison. Study 2 is based on my learning outcomes from Study 1, the second study had not been pre-planned; again the process is outlined in Figure 3.1 below.

The themes identified in Study 1 (generated from staff and relatives of two homes considered together) were then mapped onto the themes found in Study 2 for a cross-case comparison in Chapter 8, following Stake's (1995) case study methodology. Decisions regarding how best to present the data became clear as the project and data evolved. Employing a case study approach to the study enabled the researcher to gain deeper understanding and a further exploration of the experiences of the participants and the quality of life and human rights of the individuals living with advanced dementia within the contexts of the care homes.

Figure 3.1 provides an outline of the design of Study 1 and 2. Ellipses represent an intrinsic case.
Green outlined rectangles represent unit of data analysis i.e. in Study 2, staff and relative data is analysed separately for each care home.
Red outlined rectangles represent analyses / integration of findings *across* cases for instrumental case study.



Thematic Analysis

Thematic analysis (TA) is used to analyse qualitative interview data in both Study 1 and Study 2. TA is a commonly used qualitative data analysis approach in psychology (Braun & Clarke, 2006), health care (Braun & Clarke, 2014), sport and exercise (Braun, Clarke & Weate, 2017), and many other fields. TA is widely used in qualitative research and is commonly used across a range of epistemologies and research questions which is why it is important to outline the philosophical perspectives guiding the research, as I have in the section above. The following quote from the originators of the approach demonstrates the good fit between their original intent and my philosophical approach outlined above:

'We intended our approach to TA to reflect our view of qualitative research as creative, reflexive and subjective, with researcher subjectivity understood as a resource (see Gough and Madill 2012), rather than a potential threat to knowledge production, as it arguably is conceptualised in Boyatzis' and some other approaches to TA. For us, qualitative research is about meaning and meaning-making, and viewing these as always context-bound, positioned and situated, and qualitative data analysis is about telling 'stories', about interpreting, and creating, not discovering and finding the 'truth' that is either 'out there' and findable from, or buried deep within, the data. For us, the final analysis is the product of deep and prolonged data immersion, thoughtfulness and reflection, something that is active and generative. We emphasised that themes do not passively emerge from data to capture this process.' (Braun & Clarke 2019, p. 591).

TA is a method for identifying, analysing, organizing, describing, and reporting themes found within a data set (Braun & Clarke, 2006). Part of the flexibility of thematic analysis, as described in the quote above, is that it allows researcher judgement to generate themes in a number of ways, which is highlighted by Appleton & King (2002) in Table 3.1, where the researcher as the instrument is open, responsive and flexible towards the data.

This approach was selected for this project as the aim was to present participants' daily lived experiences and capture the unknowns, rather than hypothesis testing. Through its theoretical freedom, thematic analysis provides a highly flexible approach that can be modified to the requirements of studies, providing a rich and detailed, yet complex account of data (Braun & Clarke, 2006). One of TA's advantages is the opportunity to use both deductive coding and inductive coding.

Patterns of meaning within data can be identified in one of two primary ways in thematic analysis: inductive (bottom-up) or deductive (top-down). Within this project, it was intended that the inductive (bottom-up) approach would be the primary method of analysis, in that no pre-determined codes or codebook would be constructed. An inductive approach means the themes are based in the data themselves, and not driven by the researcher's theoretical interest in the topic area (Braun & Clarke, 2012). An inductive approach is therefore a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions. In this sense, this form of thematic analysis is data-driven. A deductive (top-down) approach is driven by a preselected theoretical framework, which tends to be driven by the researcher's theoretical or analytic interest in the area and is thus more explicitly analyst-driven (Braun & Clarke, 2012). In this project the decision was made to adopt the reflexive TA approach, where the researchers' role as described by Braun & Clarke (2019) is at the heart of the approach. According to Braun & Clarke (2019) the reflexive TA is not about following procedures 'correctly' (or about 'accurate' and 'reliable' coding, or achieving consensus between coders). The approach is about the researcher's reflections and engagement with their data and their reflexive and thoughtful engagement with the analytic process, aiming to develop a richer reading and understanding of the stories told within the data (Braun & Clarke, 2019).

The six-step process (Braun & Clarke, 2006), followed to analyse the data is outlined in Table 3.2. The newly introduced *'reflexive'* TA (Braun & Clarke, 2019) exists throughout the whole process of the data analysis, although one step was renamed to reflect the active role of the researcher in generating themes. The six phases were followed throughout the analysis process; however, this was not a rigid or linear process. During data analysis, I did not necessarily move through each step in order. I moved from one step to the next, and then back again. This is described in Braun & Clarke (2019) as a continual process of 'bending back on oneself – questioning and querying the assumptions' (P594) that are being made about the data, referred to in Table 3.1 as inductive analysing (Appleton & King, 2002). I moved back and forth between these steps many times during data analysis before reporting the findings.

As TA does not require the detailed theoretical and technological knowledge of other qualitative approaches, it provides a more accessible form of analysis, particularly useful for those early in their research career (Braun & Clarke, 2006). Braun and Clarke (2006) and King (2004) argued that thematic analysis is a useful method for examining the perspectives of research participants, highlighting similarities and differences, and any unanticipated findings. Thematic analysis is also useful for summarising key issues of a large data set, as it forces the researcher to take a well-organised approach to handling data, which supports a clear and structured final report (King, 2004).

Table 3. 2. Phases of Thematic Analysis (Braun & Clarke, 2006, 2019)

Phase	Description of the process
Step 1: Familiarising yourself with the data	Reading and re-reading the transcripts, highlighting significant quotes to re-visit.
Step 2: Generate initial codes	Writing down initial ideas. Coding the data and organising into possible groups.
Step 3: Searching for themes (2006) Generating initial themes (2019)	Examining the codes and grouping into initial and potential themes and sub themes. The name of this step was updated in 2019 to reflect the active role the researcher takes in identifying the themes, rather than them emerging passively from the data.
Step 4: Reviewing themes	Discussing, modifying and reviewing themes with the supervisory team.
Step 5: Defining and naming themes	Identifying the essence of each theme. Noting what each theme is telling us about the data.
Step 6: Producing the report / writing up	Reported the findings in published articles (chapters 4, 5) and in the presented thesis (Chapters 6, 7).

Ethical considerations

The researcher's position in the care home

In terms of my ethical approach to the research, it was important that my presence did not feel out of place, a threat, or an intrusion to residents, relatives, and care staff. I wanted to establish a relationship of trust and confidence with all the stakeholders. Accordingly, during the course of this project, I spent extensive periods of time in the care homes to ensure that I was a familiar face in the care homes, where my presence would be part of the everyday routine and practices.

Consistent with the methodology outlined in Table 3.1, I adhered to ethical behaviour to protect the privacy and confidentiality of everyone involved. I considered how a person being visited in their home by an outsider may feel and I was respectful of the position that I held. As the researcher, I was anxious to get to know the residents and spend time with them, to ensure that my presence was familiar, as I did not want to cause any distress. As the researcher I understood the vulnerability of all of the key stakeholders on this project and recognised how my positioning could be perceived as a threat. I recognised the vulnerability of the residents living with dementia, and that my presence as a complete stranger in their ‘home’ could pose a potential risk to their privacy and security. Family members were vulnerable and could have felt under pressure to partake in the project, with anxieties about how their involvement or not, and what they might say, could impact on the care of the resident. I also was mindful of the vulnerability of staff members, who may also feel under pressure to partake as an extension of their job roles, due to the agreement their employers had with the University.

With the aim of breaking down ‘barriers’ and becoming a ‘normal’ part of daily life in the care homes, I attended formal meetings at each care home to introduce myself and the project. I then continued to visit each care home on a regular basis, ensuring that project information was readily available on the households and around the care homes. I made sure that the information was always displayed around the home, along with my photograph and contact details, to ensure everybody knew who I was as the researcher, the aims of the project and that I was available to talk to. I understood this research project was asking people to open up their ‘home’ to me and I wanted the aims of the project and myself as the researcher to become as familiar as possible.

The project information was also displayed in the entrances of the care homes and at the reception desks. Once I had ethical approval from the appropriate authorities, ahead of any data collection, I regularly attended the care homes, becoming a familiar face and getting to know residents, families, and care staff. I would get to know the residents, family members and care staff as individuals and learn about their backgrounds, their history and about the daily running of the care homes. As a person who was initially an ‘outsider’ at the care homes, I was mindful that I was entering a person's home and I always viewed this position as a privilege.

Residents would approach and communicate with me, and I would sit and spend time 'being' with them and join with the activities that were being organised. During the day, I would sit with residents and their family members who would tell me about their personal history, their achievements and items they considered especially comforting to them at the home. This process was also important in getting to know the families and an opportunity for them to get to know me as an individual and as a part of this project. It helped the family members and the staff to know about me outside the formality of being the 'researcher' or 'PhD candidate'. Spending this time together allowed for much discussion and I could demonstrate that I was there for this purpose – to get to know their everyday experiences and this was the way of breaking down barriers, providing reassurance if needed and also breaking down some of the stigma that was held around the research process being a 'clinical' process. It is important to note that this time spent in the home, interacting with residents and relatives, was not part of a formal process of observation. I was not undertaking an ethnographic or participatory action research study (Jones & Smith, 2017; Williams & Keady, 2021); the aim was simply to help residents and relatives and staff feel at ease with me, to enhance the richness and value of the formal research interviews and (in Study 1) observations of residents. This time was also valuable to me as a reflexive researcher, providing a rich context for my subsequent analyses of the research data and understanding the complex systems operating in each home (Appleton & King, 2002; Tubey et al., 2015). Stake also discusses the importance of studying 'how things work', within settings, contexts and in relation to groups of individuals (Stake, 2010, p.2).

Ahead of carrying out my research work for Study 1, I undertook a full staff induction, over two days in total, working alongside the staff members on various households, where I could truly understand the daily routine and procedures of the care homes. This was a requirement of the sponsoring organisation for Study 1. On my induction days I was able to witness and appreciate daily challenges faced by both care staff and family members, which helped reassure them that I was there to give them a platform to talk about their experiences. The induction involved familiarisation with the care home as a whole and each individual household. The staff explained the aims and objectives of each individual household and the variety of care needs. Whilst getting to know each household, care staff took the time to explain different objects around the home, which belonged to individual residents, and provided some history about the residents' backgrounds. As part of the induction, I assisted care staff with small tasks, such as making and serving afternoon tea for residents and families. During the induction, I had the opportunity to sit and talk with individual residents on different households throughout the day and partake in arranged activities, alongside the activities co-ordinator.

Outside of the induction days, I did not engage in providing personal care for residents. If an urgent need arose I sought staff input wherever necessary. Throughout the time I spent at the care homes, I did co-organise coffee mornings/afternoons and fundraising events with activity co-ordinators. My aim with this was to secure an additional opportunity to meet relatives and spend time with people at the homes and to further understand the daily experiences and challenges faced by stakeholders. During these events, I would be regularly approached about the aims of the research project, and what partaking would involve. Partaking and co-arranging these events was also a further opportunity for potential participants to become familiar with my presence and for us to get to know each other outside of the remit of the project. I was aware that this process for many was the first time that they had been involved in research and I wanted to ensure that the experience was positive and non-intrusive. There were many days where I offered to re-schedule appointments with participants, such as days where a resident was unwell or I knew a household was short staffed for example. I wanted participants to 'want' to partake and not to feel under any additional pressure.

Information sessions were held with the care homes partaking in both studies, where I would attend the care homes and discuss the project. I ensured that I was available to answer any questions regarding the research and ensured that information was widely shared around the care homes.

As the researcher on this project, I was mindful of the position held and the pressures that could possibly be felt by staff members and relatives to partake, and the possible anxiety about the negative implications on them, should they not want to be involved. This was a particular concern with those homes managed by the sponsoring organisation. Perhaps I would be seen as reporting anything said to me to 'the management'. With the aim of minimising these concerns, I had open discussions regarding the project aims and reiterated to staff and family members that any involvement would be voluntary, and any information given would be confidential and anonymised. I was always clear that even if they decided to partake, that their consent could be withdrawn at any time.

I talked to staff and family members regarding their involvement, as an opportunity for them to have their voices/experiences heard by an independent and trustworthy researcher outside of the care home organisation, who was familiar with the context and their situation. A key part in these discussions was reassuring the staff members (more than families), that there were no 'correct' or 'incorrect' answers, and that their experiences were valuable to the research project. I felt that it was incredibly important for participants to know that their contributions were valid, and their answers were not perceived as 'correct' or 'incorrect'. To further put potential participants at ease, I would leave a copy of the topic guide and gave them time to discuss questions in advance.

I was also accepting of the fact that family members and staff members in some instances were happy to spend time in my company but did not want to partake in the project.

Inclusion of people who lack capacity to consent

The Mental Capacity Act (2005) states that research with individuals who lack the capacity to consent must have the ethics of the research scrutinised and approved by an appropriate body. To gain approval for this research to go ahead, the four conditions below had to be met and approved by the ethics committee.

1. The research must be connected with an impairing condition affecting the participant or its treatment.
2. Research of equal effectiveness could not be carried out if confined to participants with capacity.
3. The research must either: (a) have the potential to benefit the participant without imposing a disproportionate burden, or (b) provide knowledge of the causes of, or treatment or care of others with, the same or a similar condition – in this case the research must involve negligible risk to the participant, not interfere significantly with their freedom of action or privacy, or be unduly invasive or restrictive.
4. Arrangements must be in place to comply with section 32 (consulting carers) and section 33 (additional safeguards).

In Wales, the appropriate body must be a research ethics committee recognised by the Welsh Government. In relation to this project, an application was made and approved by the Health & Care Research Wales, Wales Research Ethics Committee 5. During this process, I worked with my supervisory team to submit the initial application, following approval from the University School of Healthcare Sciences Ethics Committee, and attended a meeting with the committee to discuss my application, for Study 1. Following the meeting, the committee gave a favourable opinion subject to minor amendments to the project documents. Once changes were made to the documents as requested, ethical approval was given. The Committee were content that the study met the requirements of the Mental Capacity Act (2005), in that it was concerned with an impairing condition (dementia), could not be carried out with people with dementia who had capacity and would add to understanding of dementia care without posing a significant risk or being unduly burdensome to participants. They were also satisfied with the arrangements for consultees. In order to proceed with Study 2, I submitted a substantial amendment alongside my initial ethics application. The substantial amendment form contained details of the proposal for Study 2 as the project had received PhD funding. The ethics committee approved the proposed amendments without further meetings with the committee.

For Study 1, it was planned to directly include perspectives of residents, through direct observation and interaction. It was considered likely that the individual residents may be unable to give consent themselves and therefore an assessment of capacity was undertaken. Assessment of capacity included four parts, asking does the person have the ability to:

- understand the information relevant to the decision,
- retain the information,
- use or weigh the information to arrive at a choice,
- and communicate the decision.

A checklist was prepared to complete while undertaking the consent procedure, a copy is provided in the appendix – appendix M. In all cases where a lack of capacity was identified during this process, a suitable representative (a ‘personal consultee’), a near family member or relative was approached to give an opinion on the person's likely views regarding participation in this project. Provision was also made for ‘nominated consultees’, an independent person (e.g. social worker or advocate) to advise on the person’s involvement if no personal consultee was available. In the event, consultees were all family participants during this study, as they all had close contact and good knowledge of the person living with advanced dementia, which was a requirement of the inclusion criteria. A condition of ethical approval was that any advance statements concerning research should be respected.

Although residents participating did not have capacity to provide consent, it was very important to monitor throughout their involvement any indications of distress or of unwillingness to participate, and of the potential for their involvement to be suspended or withdrawn if need be. In relation to Study 2 consent for resident participants was not sought as the study did not directly involve the residents, only their family members and their professional caregivers.

Observation of residents not participating or consented to project

Observations in the care homes were part of the research procedure in Study 1 only. Families were informed of the project being carried out in the care homes in advance of the researcher going into the care homes. Information regarding the research project was readily available in the care homes with further contact details for those who wanted further information. Prior to any research being carried out, the researcher held talks about the project at the care homes and attended meetings with the families and staff to discuss the project and answer any questions that individuals may have had.

Following helpful discussions with the H&CRW Ethics Committee, a process was put in place to inform the residents' next of kin/ relatives that an observation would be taking place as part of the project; and offered an opportunity for residents and relatives to opt out from being observed if they were not taking part in the study. This was included in all the Information Sheets, and I arranged to present the project at Relatives' Meetings in the Homes. Whenever a period of observation was about to commence, I informed all present so that they had the opportunity to opt-out at that time as detailed in the project information sheet:

"Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish". Consultee information sheet [appendix G].

Observations of residents partaking in this project were made in public places throughout the daytime and not during periods of intimate care. It is important to note that no video recordings of the observations were made during the field work. Only observations of residents who had consent in place were made with the use of the AwareCare tool (Clare et al., 2012). As indicated above, ahead of making observations I would inform the household that an observation would be taking place and I had explained in advance what would happen during this process.

Both participants and non-participants had seen the AwareCare tool (Clare et al., 2012) ahead of observations taking place. Still during this time, I considered that periods of observation could possibly alter the practice of staff during observation. However, residents, families and care staff had become very familiar with my presence on the households during their everyday activities and I could see that their behaviour was not altered for the benefit of the observation period. Whilst observations took place, I was considerate of the effects on residents nearby who were not being observed. Naturally, there were residents who may have wanted to interact, or an incident would occur and the observation taking place would need to stop or pause momentarily. An example of this would be a resident nearby may require support from a staff member and I would inform a staff member, who would come and provide the support required. Where staff members were nearby, they would distract residents who may have been attempting to interact with me during periods of observation. However, I was very aware of my position as the ‘outsider’ in their home. I would reassure staff that there was no need for them to stop providing their usual care to residents on the household, due to my observation period.

Procedure for raising concerns

For participants and potential participants information regarding complaints and concerns regarding the project were included in all participant information sheets.

Should I have witnessed anything that would be considered abuse or neglect, a procedure was agreed where I would report to the care home manager in the first instance and follow the care homes’ usual procedures for reporting. I would also report any incidents to the supervisory team. If the supervisory team and the care home organisation were to decide the matter should be escalated further, it was expected that I followed their advice and comply with the usual reporting regulations.

During the project, I did have to undertake this procedure and report an incident to the care home and the supervisory team. The researcher was aware that the reporting procedure would, and did, effect the trust that had been established between myself and the staff working at the care home. I was very aware of the implications of reporting such an incident and the effect it could possibly have on the outstanding data collection. However, the well-being and the safety of the residents were the over-riding priority.

The procedure for reporting Serious Adverse Events (SAE'S) is included in Appendix FF

Pressure on staff to take part

As a researcher within this setting, I understood the importance of the pressure that could be felt by staff to partake in the project and concerns that it would affect their employment. In acknowledgment, I spent time with the staff prior to any research work being undertaken. During the time we spent together, the staff would discuss their roles, their aspirations as carers, and would ask questions about the research. I took this opportunity to assure the staff that the main aim of the project was to capture the residents' quality of life and the residents' lived experiences. I was careful to communicate with staff members that they were not under any obligation to partake in the project as an extension of their job roles at the care homes, and their decision to partake, or not, would be voluntary and not discussed with their employers. Further, I was mindful of the interest that staff members had in the research, and was understanding to any concerns that they had around the University's partnership with the organisation, concerning their anonymity and confidentiality, and sought to reassure them accordingly.

Confidentiality and anonymity

Confidentiality and anonymity were discussed with potential participants during this project, although a number of participants appeared unconcerned. Time was spent getting to know individuals ahead of their participation in the project, where trust was established between myself and the participants. I would answer any questions or queries that the potential participants had regarding their involvement with the project. Additionally, I would read over the information sheets with potential participants, highlighting exactly how their confidentiality and anonymity would be maintained and what would happen to the digital recordings made of interviews. Where potential participants agreed to take part, a time/date would be arranged. Also, a preferred location for interview would be arranged with participants, to ensure a space was available where they felt comfortable and able to share their experiences in confidence and in privacy.

The anonymity and privacy of participants in the research is respected and was also explained in greater detail within the information sheets received by all potential participants. Anonymity of the participants has been upheld, as any information that had potential to identify those participants, such as naming care homes, names or job titles, have been replaced with pseudonyms. The name of the care home organisation sponsoring Study 1 is a matter of public record and has not been pseudonymised.

Conclusion

This chapter has set out the major considerations underpinning the two empirical research studies that follow in Chapters 4 and 5 (Study 1) and Chapters 6 and 7 (Study 2) of this thesis. It demonstrates how my philosophical approach to the research is reflected in the methodology adopted and the ethical stance taken, and highlights the major theoretical perspectives introduced in Chapter 1. It shows the progression of the research from Study 1 to Study 2 and highlights the potential for the results of the two studies to be brought together in the final chapter of the thesis (Chapter 8).

Chapter 4: A Collaborative approach: Care staff and families working together to safeguard the quality of life of residents living with advanced dementia

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Introduction

In 2014, an estimated 311,730 persons with dementia were resident in care homes in the UK, making up seventy percent of all care home residents (Prince et al., 2014). Given the increased prevalence of the condition with age and an ageing population with longer life expectancy, the number of people affected by dementia continues to grow. Care home placement is often required as individuals progress into the later stages; as the average age of people with dementia becomes older, there is an increased risk of care home placement being required due to the greater likelihood of physical health comorbidities and of outliving potential care partners (Edelman et al., 2005; Moyle et al., 2007; Samus et al.,2005).

In recent years, quality of life (QoL) has become a major focus of research on dementia (Ettema, Dröes, & de Lange, 2005; Jing et al., 2016; Moniz-Cook et al., 2008; Algar et al.,2016). There is also increasing attention on well-being and rights of people living with mild to moderate dementia, yet, despite this, we understand much less about how to identify and support well-being and human rights in people with advanced dementia (Clare et al., 2014). It is crucial not to overlook the needs of those at their most vulnerable in the later stages of dementia, particularly where individuals are completely dependent on others and may be unable to verbally communicate their wishes.

Individuals living with advanced dementia are at increased risk of having their rights overlooked. Kelly (2005) found a lack of support for individuals living with advanced dementia in care homes in contrast to other terminal illnesses (Kelly & Innes, 2013). The right to dignity, autonomy and protection from abuse is universal, regardless of the cognitive or physical decline (Kelly, 2005; Kelly & Innes, 2013; Mitchell et al., 2004). Reduced cognitive function threatens the right to autonomy, so that people living with dementia are reliant on surrogate decision making, whereby family members and care staff become their decision makers. This process may lead to their human rights not being continuously considered (Robinson et al., 2007). This may not necessarily be a deliberate act, as situations may occur where an organisation's practices and procedures disadvantage a certain group of people; this is known as 'indirect discrimination' (Devlin et al., 2007). For example, people living with dementia may be excluded from making decisions regarding their care planning. Regardless of the intentions, the effects are severe and have been termed as 'social death' (Sweeting, Gilhooly & 1992). A self-advocacy organisation for people living with dementia has suggested that there is a negative perception of human rights, coupled with a lack of understanding (DEEP, 2016).

Moving into a care home setting leads to changes in a person's social and physical environment, which may result in changes to their QoL. Care homes are able to provide various facilities and professional care for individuals living with dementia, high-quality care provision and person-centred care (Winzelberg et al., 2005). Despite this, research comparing QoL of individuals living with dementia in the community with those living in care settings reports that living in the community is associated with higher QoL (Nikmat et al., 2015; Winzelberg et al., 2005). Factors contributing to QoL, e.g. higher levels of independence and social inclusion, differ for individuals living in the community compared with those residing in care home settings (Nikmat et al., 2015; Kuo et al., 2010). Living in the community allows individuals to maintain a role in family life, a place in the community and social connections. Contributors of QoL may be different in the later stages of dementia, where factors in the early stages, such as independence, may be less significant, and safety and comfort may take primary importance (Volicer, 2007). Therefore, it is necessary to understand the factors affecting QoL, to support and maintain QoL (Borowiak & Kostka, 2004) for those individuals who progress into the later stages who require care home placement, and who receive increasingly intensive care (Jing et al., 2016). Alzheimer's Disease International (2009) states that research is well established with other chronic diseases, but the quality of life has not been widely included in investigations of advanced dementia.

Alzheimer's Disease International (2009) categorises different stages of dementia by different levels of impairment and health care needs. Research suggests care homes are having difficulty supporting residents with advanced dementia (Engel et al., 2006). This is due to little advanced care planning and lack of knowledge of residents' distressing symptoms, which becomes increasingly challenging for care providers (Engel et al., 2006; Mitchell et al., 2004). Identifying care preferences combined with increased care planning and specialised training could contribute to better care provision for residents living with advanced dementia (Mitchell et al., 2004).

Aim

This study aimed to explore the quality of life and well-being of care home residents living with advanced dementia, and to explore how personalised care can be achieved when the person is completely dependent on others for care and may no longer be able to verbally communicate their wishes. We also explored how individuals' choices and rights were upheld and how staff or relatives dealt with decisions made in the best interest of a person with advanced dementia. This study provides an opportunity to consider human rights in dementia with the aim of identifying what supports a positive cultural shift, from risk of abuse of human rights to promotion. This article focuses on qualitative interviews conducted with family members and care home staff supporting people living with advanced dementia.

Methods

Design

The research took place across 2 specialised dementia care home facilities, operated by an independent care home group in North Wales. The 2 care homes comprise of individual households for people living with dementia. One care home has 3 households, with the capacity for up to 32 residents, and the other home has 4 households with the capacity of up to 48 residents. The research arose from a partnership with the care home group as part of the Knowledge Economy Skills Scholarship (KESS 2) programme. The KESS 2 is a major European Convergence programme led by Bangor University on behalf of the Welsh higher education sector, offering collaborative research projects (Research Masters and PhD) associated with a local company partner.

Measures

An initial assessment to assess the severity of dementia of the residents living with dementia involved using the Clinical Dementia Rating (CDR) scale (Morris, 1997). The CDR assessment was rated by the researcher from information provided by care staff. The CDR was introduced by the researcher as part of the research project. Staff were able to indicate possible residents who would meet the criteria. The CDR scale is widely used and measures stages and severity of dementia with 0 indicating no impairment and stages 0.5, 1, 2 and 3 indicating questionable dementia, mild, moderate and severe dementia, respectively. The scale includes 6 domains: memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care (Morris, 1997). Care staff also completed the Functional Assessment Staging (FAST; Sclan & Reisberg, 1992) on each individual in the study. The FAST procedure encompasses the progression of Alzheimer disease in 7 stages.

The FAST stages begin at (stage 1) normal to (stage 7) severe dementia. Residents meeting the criteria for advanced dementia in this study were expected to meet criteria 6 or 7.

Ethical Issues

Following ethical approval from the North Wales Research Ethics Committee (17/WA/0015) February 17th, 2017 eligible participants were approached by care home managers and the researcher. Information leaflets and posters were available throughout the home. Potential participants were given information sheets along with consent forms in Welsh or English depending on preference detailing the aims and procedures of the study. Following discussion of the project with the researcher, written consent was sought from relatives and staff members prior to interviews. All participants provided consent to take part in the interview, including consent for audio recording of the interviews.

Participants

Family members of residents living with advanced dementia (CDR 2-3; FAST 6-7) were identified by the care home managers and senior care staff. Relatives of a resident were invited to participate if they had regular contact with their relative in the home, to ensure good knowledge of the individual's lived experiences. Several participants expressed an interest in taking part independently. Where possible the researcher recruited a relative of the resident and a staff member to provide information about the same resident during the separate qualitative interviews. In each case, the researcher made participants aware that their involvement was voluntary and if they chose not to participate, this decision was fully respected by the researcher. Care staff members had to have good knowledge of the resident and their daily lived experiences. All residents who were eligible to partake were approached to take part in the wider research project. From eighty possible residents living at the homes, 13 were identified as eligible and 10 were involved in the project.

Participant Characteristics

Data were collected from 16 participants made up of 8 relatives and 8 staff members. Data collected from relatives included 7 spouses (four female, three male) and one female adult child aged 57-81 (mean 72 years). All were white European origin, and all spouses had retired, with 1 adult child in clerical occupation. Participating relatives had contact with the individual living with dementia at least four days a week. The staff participants comprised 5 care assistants, 1 care practitioner, 1 nurse and 1 activities coordinator, seven female, one male aged 21-66 (mean 43). Participating staff members worked full-time hours and were in contact with the resident a minimum of three days weekly. Two relatives who had intended to participate, did not do so, due to the death of their relatives between recruitment and the research commencing. One relative declined, as she struggled to come to terms with her husband's condition as well as care home placement. Three care staff members declined to take part, anxious regarding giving incorrect answers, possible repercussions of talking about their employment and not having enough time. The sample size was determined by the residents who met the criteria for advanced dementia and the willingness of their relatives/key staff members to participate.

Semi-Structured Interviews

The researcher conducting the interviews was a familiar face within the homes, attended resident family meetings and undertook induction shifts at both homes. The researcher continued to see participants at the home after their scheduled interviews as it was part of a wider project thesis. Therefore, the researcher had the opportunity to build a rapport with participants before, during and after interviews. Interviews conducted lasted between 20 and 80 minutes, and the interviewer advised participants that they could ask any questions during the interview and that there were no correct or incorrect answers. If participants were unsure, the interviewer would explain further and participants were encouraged to talk about the subject area as they wished. To assist participants respond to the human rights questions, the researcher provided participants with a copy of the DEEP "Our Dementia, Our Rights" guide, written for and with individuals living with dementia, setting out simply the key domains; equality, inclusion, privacy and security, dignity and the right to life.

A topic guide (Table 4.1) was developed through consultation with the project research team and advisory group of individuals living with dementia. Semi-structured interviews with participants were on a one-to-one basis with the researcher in the care homes. During interviews, participants were able to express their thoughts and feelings on other related topics.

Table 4.1. Semi-Structured interview topic guide for relatives and staff members

Interview Questions
How is well-being expressed in the individuals?
How is QoL and well-being monitored?
If you are making a decision on the individual's behalf, what is the reason for this?
How do you know when you are making a decision on this person's behalf that it is in the best interest of the individual?
What is the assumption you make about the individual's ability to make decisions about their daily lives?
What are your views and experiences on human rights in advanced dementia care? - How are they maintained and promoted
Does living in a care home make a difference to living in the community, in terms of human rights?

Data Analysis

Interviews were transcribed from digital recordings and all personal identifiers removed to retain anonymity and participants were each assigned a pseudonym and participant number. The researcher listened back to digital recordings after transcribing to ensure accuracy of the coding. The qualitative research software programme NVivo was used to support coding and analysis of the data to enhance rigour (Richards & Richards, 1991).

An inductive thematic analysis approach (bottom up) was adopted (Braun & Clarke, 2006), and a framework was used for identifying and coding words and phrases of importance. The researcher identified some themes that were linked to the topic guide during the coding phase of the analysis. Therefore, an inductive and deductive approach took place during the course of data analysis.

The potential themes were identified before further analysis using the NVivo software to support coding of the data and identifying emerging themes. During this procedure, the researcher placed extracts of the interview transcripts into nodes identifying initial themes. The themes were reviewed to ensure the extracts fitted the given theme, and no further relevant extracts were within the data set (Braun & Clarke, 2006). The researcher coded the data independently and met regularly with the research team to discuss the coding process, themes and subthemes. The themes and subthemes were refined and modified with the research team to ensure trustworthiness, and a final consensus was reached.

Participant Validation

Following the data analysis procedure, participants were invited to discuss the project results and provide feedback. This provided meaningful feedback from participants to assist the researcher in developing the interview topics for further research and validation of the participants (Horsburgh, 2003). Preliminary findings were presented at the care homes, where participants and others were able to give their views and ask for further information, if required. During discussion attendees confirmed that the findings of the research did resonate with their experiences and therefore no further changes or analysis was considered necessary. The researcher ensured that the findings were written in accessible language as highlighted by Langdridge (2007).

Results

The themes (see Table 4.2) incorporate views of the relatives and care staff relating to individual residents. Although the themes identified were the same, sometimes the staff and relatives offered a different perspective.

Table 4.2. Themes and Subthemes

Theme	Subtheme
Well-being	Physical signs of well-being Who S/he used to be
The Girls	Staff and relative relations Family involvement
Communication	Importance of communication between staff, residents and relatives
Human Rights	Decision making

Well-being

Relatives and staff members identified factors that they associated with the well-being of the individual residents. Within this theme, two subthemes have been identified. The first of these related to *Physical* signs of well-being such as food and fluid intake and body language, which were described as indicators of the person doing well. Some staff and relatives related eating well with the resident's well-being. Relatives discussed how a number of residents who would refuse to eat and drink at home, had improved since being at the care home receiving support from the care staff.

'We were seeing the dietician three days a week and they (dieticians) came on Saturday and said can't believe the weight he's put on he wouldn't even eat at home for you. But he's put that three stone back on in the year' (since care home admission) (P7, Wife).

The care staff commented how they were able to see the physical signs of the residents' well-being through body language, as well as verbally.

'He does chuckle and he does smile. His eyes do light up when there's… I mean he does sort of chat as well, and say things, and join in. So you know, that's the way I think he expresses his well-being really. He does laugh and things. He can express. You can see that yeah' (P9, Activities coordinator).

However, one staff member commented:

'He doesn't show us any emotions, he is expressionless' (P12 ,Care assistant).

Care staff explained how working on one household, allowed them to recognise individual residents' typical behaviours.

'If he's really not happy about something he'll have that really angry look on his face. With brow furrows and everything, and other times he's, you know, he'll throw his rubix cube and smiles, you know, so you can tell, he's got that cheeky twinkle in his eye' (P16, Care assistant).

The second sub-theme of well-being was, '*who s/he used to be',* this related to moments where participants could see the individual irrespective of their dementia. Relatives and staff members referred to residents' interactions as a sign of their well-being. Relatives shared the enjoyment of these moments:

'She'll come out with all four of them (children's names), so you get these moments it's what you come for really. You know, those little moments and she comes out with vintage Shirley, you know' (P8, Husband).

Sharing these moments with the residents is comforting for families, and staff members are able to connect with who the residents used to be, as well as the here and now.

'You know her old character, who she used to be. It is nice to see her in good spirits, you know, displaying ways she used to be. The way she was at home in a way, you know, mischievous' (P8, Daughter).

The Girls

The care staff members were referred to by the participants as 'The girls'; a term of endearment used by families, regardless of the number of male workers at the care homes. Within this theme, two subthemes were identified. *Staff and relative relations* and *Family Involvement*. The first of these referred to the rapport between the care staff members and the relatives. Relatives commented how the care staff knew their personal preferences and adhered to them:

'And the girls will try and coordinate things and match them because they know that's how I am and that's how she used to be. So you know little things like that' (P2, Husband).

Some relatives commented on how the care staff carry out their roles, that it was more than a job to them.

'They do it naturally here these girls, don't they. They put their arms round them you know' (P1, Husband).

Staff members valued their relationship with the families on the households.

'There's a lovely rapport between the family members on (household) and the staff and you know more like a family really' (P9, Activities coordinator).

The care staff not only supported the residents in the care home but the family as a whole.

'We have a laugh with the staff as well and you might not be able to do that elsewhere and it helps. You know little things like that makes it lighter for us as well' (P8, Daughter)

The relationship the care staff have established with the relatives encouraged *family involvement*.

‘We come to help them at lunch times. Because they’ve got so many that need feeding. If I can give Maureen, then that will save them then doing Maureen. When I’m not here then okay fine’ (P2, Husband).

Care staff and relatives commented that their relationship allowed the households to be individual homes with individual communities.

‘It’s easier isn’t it when you’ve got family members here, who have got their, you know, knowledge of, you know, the person. And what their interests and likes or dislikes or.. any, you know, that’s first-hand knowledge isn’t it really’ (P9, activities coordinator).

Communication

Within this theme, one subtheme focused on the *importance of communication* between residents, care staff, care home managers and families. The staff commented on letting residents know what’s happening and providing them with reassurances.

‘Communication is key. It’s key in dementia care. Letting them know what’s happening and you know talking through things’ (P9, Activities coordinator).

Families discussed residents’ preferences and routines with the care staff.

‘I work well with these guys so if I’m not here what I’m doing is asking them to get her up before 11 because she hates personal care’ (P1, Husband).

Care staff monitored the resident’s well-being and communicated with the rest of the team and relatives about the individual.

‘I would speak to everyone else and the nurses and the relatives, and check back with the documents and stuff’ (P18, Care practitioner).

Relatives and care staff discussed how they communicated well with each other about the resident’s daily care.

‘There’s a disconnect between the care staff and the nursing staff. Has she had her medication? Oh I don’t know, I’ll go and ask the nurse’ (P1, Husband).

In relation to *communication*, the care staff and relatives recognised the resident’s perception of events may be different.

'But it's amazing how they use their body language to tell us that there's something not right' (P12, Care assistant).

Relatives and care staff recognised the resident's different perception may lead to unexpected responses.

'So if she doesn't like you, It doesn't mean she doesn't like you because the next minute she wants to kiss you' (P7, Husband).

The care staff appreciated the different ways residents interact with them, recognising that what they say may not necessarily be what they are trying to communicate.

'There's other days where he would just say yes. And you wouldn't know whether he meant yes or no. But yeah that's what you think but that isn't probably what they are thinking' (P13, Care assistant).

Human Rights

Participants discussed how *human rights* were maintained and promoted within the care home settings.

'Well they would be the same really at home with me wouldn't they? But then I would be getting him out every day' (P7, wife).

One participant commented on the discussion surrounding human rights at the care home.

'I don't think anybody ever talks about human rights, no need probably' (P 1, husband).

A number of relatives discussed how their residents' human rights have improved, since being at the care home.

'I feel that she has more rights here I think, because if she was living at home she wouldn't have that care would she' (P8, daughter).

Relatives discussed the importance of the continuity of care, which is what their relatives received within the home.

'They do change staff but the majority of them are on this floor all the time. So it's not that again strangers keep coming in and going out all the time you know' (P2, husband).

However, some participants did consider that human rights must change following moving to the care home. They referred to care homes as institutions and although, it may not be a deliberate act, institutionalisation can take over the identity of the individual.

'They have to change, at home I was in full command. I see certain things, but it can't be done, because there's not enough staff on. I came in today and he had this Rugby shirt on, it's very easy just shoving an old T shirt on but I don't like that. He was always a gentleman and that's my James, and I want him to be seen as a gentleman (P3, Wife).

Because the care home staff were attempting to meet the needs of a number of residents at the same time, the same relative noted that there were occasions when meeting the needs of one resident impinged on the rights of others:

'Three is not enough (referring to the number of care staff on a household) there is very disruptive residents here, then two of them have to assist. Leaving one in the lounge and they've got a number of residents here, who can be very disruptive and having one person to deal with that is not enough. Not good enough, it's not giving the rest of the residents enough attention' (P3, Wife).

In relation to *decision making*, where decisions had to be made on behalf of the resident, relatives made decisions based on their knowledge of that person, personal preferences, past experiences, and arrangements they had made prior to care home placement.

'You have to make decisions on their behalf and you do it hand on heart. And you hope that that is what they would want you to do' (P7, husband).

The care staff explained that they would discuss any decisions with the relatives.

'I mean we wouldn't do anything that we would know (husband) wouldn't be happy with, again working together with everyone' (P 10, Care assistant).

Discussion

Summary of findings

This study aimed to explore the quality of life and well-being of people living with advanced dementia in care home settings. This included an exploration when the person had limited or reduced capacity of the safeguards that were in place to ensure their rights and choices were at the forefront of care.

Well-being: The relatives and care staff members discussed factors they associated with the residents' well-being and QoL. Indicators of residents' well-being were derived from ‘physical’ indicators: food and fluid intake, mood, interactions and facial expressions such as smiling, laughing, eye gaze, verbal and nonverbal behaviours. Furthermore, families placed an emphasis on moments of clarity and identity ‘who he or she used to be’ as markers of well-being. The previous research findings suggest higher ratings of QoL are associated with responsiveness (Clare et al., 2014), social contact and activity (Astell & Ellis, 2006; Brooker & Duce 2000). A case study set in a care home with a lady, ‘Jessie’, living with advanced dementia indicated that although Jessie had difficulty producing meaningful conversation, she maintained the urge to communicate and participate in social interactions and activity (Astell & Ellis, 2006). Jessie’s most frequent behaviours in response to interaction were smiling, laughing and eye gaze, termed as ‘happy behaviour’. This is in line with the factors found in this study, highlighting the need for social activity to be maintained for the residents’ well-being.

Further benefits for residents’ well-being involved the physical environment (Sloane et al., 2002). Although a number of residents were not able to engage fully in a particular activity, they were able to experience passive enjoyment of the environment. Lawton (1991) placed emphasis on the effect of environment in contributing to an individual’s quality of life. The person-environment system is crucial to QoL for a person with advanced dementia in a care home (Ettema et al., 2005).

A number of residents had gained weight since moving to the care homes and relatives considered this to be a factor reflecting well-being. Sharing mealtimes provides social cues from others, which increases appetite, food consumption and pleasure (Higgs & Thomas, 2016; Pilgrim et al., 2015). A good daily intake of food and fluid, and weight gain are often used as markers of well-being (Higgs & Thomas, 2016).

Relatives in particular place emphasis on occasions where the resident showed signs of their individual character and personality, as it was prior to the onset of the dementia. Such moments provide families and care staff with a shared experience with the resident, which is an additional benefit, a type of reminiscence (Melunsky et al., 2015). Furthermore, relatives understandably compare the past with the present, reinforcing the notion that ‘they are still there’. For the care staff, who did not have any previous connection to the residents before their illness, these moments allow staff to appreciate the residents’ characters’ lives. This enabled the care staff to develop a deeper understanding of certain behaviours initially perceived as problem behaviours arising from the dementia, but which may equally be understood in terms of the person’s life story and lifestyle (Moniz-Cook et al., 2001). Understandably, the dementia journey can cause family members a sense of loss and grief for the loved one they once were (Melunsky et al., 2015). Despite this, participants found these moments of clarity as a comfort and indicators of their relatives’ happiness in the home.

‘The Girls’: The care staff were known in the homes as ‘the girls’, a term of endearment. The well-being of the residents was maintained by the girls, who were seen as providing excellent care intuitively, as reported by the relatives. Families were heavily reliant on ‘the girls’ for their support, expertise and monitoring of their relatives’ QoL as well as contributing to their own well-being. For families, care home placement comes where it is not possible for the individual to continue living at home. However, in this study, the caregiving role had changed rather than ceased for the relatives. Families in this study felt enabled by ‘the girls’ in their new caring roles. As families continued to provide care for their relatives, they became an advocate sharing their knowledge of the individual’s preferences. These findings support the triangle of care notion (Royal College of Nursing, 2014), which states that involvement of families equips care staff with better whole person knowledge and insights into how dementia can affect their behaviour and overall QoL. Family involvement is one of the most significant contributors to residents’ well-being (LaBrake, 1996). The previous research by Gaugler (2005) identified care homes where staff members recognised family needs as well as the individual living with dementia were most likely to achieve good relations with family members.

Communication: Communication between the care staff and family members is fundamental for knowledge, decision making and coordinating caregiving efforts. Despite this, families expressed a concern for the lack of communication between the nurses and the care assistants. Frustration arises from this breakdown, as the nurses held the information regarding residents’ medications but were not permanently on the households.

Care staff and family members took into account the resident may interpret things differently. For example, a resident’s distress during personal care may be a result of feeling exposed, vulnerable and a lack of understanding about what is happening to them (Adams & Gardiner, 2005). They recognised different communication narratives, such as shouting and calling out, as a sign of discomfort and not being able to express how residents were feeling in any other form. Furthermore, families and care staff discussed the different forms of social dialogue they had with the residents. They used different methods, using body language and gestures and tone of voice to communicate. They recognised that the dialogue may not much make sense linguistically but enabled the resident to remain in the social world, allowing residents to contribute to the conversation (Astell & Ellis, 2006).

Human Rights: Human rights were not widely discussed within the care homes, coupled with confusion and negative perception surrounding human rights in care homes. As reported in the "Results" section, one participant commented, 'I don't think anybody ever talks about human rights, no need probably'. A guide to the rights of people living with dementia written by people living with dementia (DEEP, 2016) suggests that people view human rights from a negative perspective, avoiding human rights violations rather than promoting them positively. Accordingly, residents' rights were considered to be maintained by the lack of signs of physical abuse, whereas bruising and scratching may be visible on care staff members. It is widely recognised that people living with dementia may fall victim to physical abuse as a result of, what may be perceived as, challenging behaviour within care homes (Brimelow & Lyons, 2009; Jones, 2000; Kelly & Innes, 2013). A negative perception of human rights prevents open discussion, and the current dialogue placed an emphasis on violation of rights rather than promotion. However, 7 family members felt that their relative's human rights within the care home were maintained. This is supported by the literature stating care homes provide an environment that involves a high standard of care, safety (Age UK, 2011; Tascón & Ife, 2008), dignity (Age UK, 2011; Department of Health, 2006; Cornwall et al., 2004), continuity of care staff members and person-centred practice (Department of Health, 2006; London, 2008). Furthermore, families commented on the staff recognition of the residents as individuals. In line with personhood theory by Kitwood (1997b), recognising individuals living with dementia as people and supporting their personhood promotes their well-being. As residents with advanced dementia in care homes are at their most vulnerable, it becomes the responsibility of the care provider to sustain and promote care practices, which enables the individual's personhood.

In contrast, there is evidence in the literature focusing on human rights of people living with dementia, experiencing a lack of dignity and rights within care homes (Glendinning, 1999; Jones, 2000; Kelly, 2005; Kelly & Innes, 2013). Despite this, the continuity within the team reassured families that decisions were taken with the resident's best interest and not decided upon by strangers. Importantly for the care team, their justification for making decisions on behalf of the residents stems from the resident's inability to make choices in support of their QoL and well-being and ensuring best interests (Royal College of Nursing, 2014).

In terms of care home practice, it would be beneficial to have more open discussion regarding the promotion of human rights. Removing the current stigma would allow residents, families and staff to discuss openly, and reflect on what their human rights mean to them.

Strengths and limitations

The exploratory nature of the research project results in a relatively small sample, with two participating care homes, both from the same care home group, incorporating a common ethos and similar day-to-day practices and a number of senior staff members working across both homes. However, this allowed the researcher to dedicate considerable time within the homes, interviewing and observing participants, becoming familiar with residents, families and care staff. The interviews provided relatives with the opportunity to share their experiences and gave care staff a chance to tell their story, allowing for richness of data to be gathered. Family members who volunteered to take part in the study were heavily involved in their family member's care and the outcomes may not transfer to relatives who may not have the opportunity to maintain, yet change, caring roles as their relative moved to a care home. The researcher became embedded within the homes; as a part of the project, the researcher had undertaken a full staff induction at both homes and was able to observe the daily running of the care homes as well as the interactions, relationships and daily challenges. During this time the researcher could observe the importance of the themes in practice.

One limitation that should be acknowledged is participation bias, as is common with all research, staff with higher job motivation were more likely to partake in this study. Also, given the high demand of workload within care homes, this could limit the amount of time the staff felt that they could provide to partake in the study. A further limitation relates to the relative lack of detailed, in-depth discussion of human rights; although we attempted to support participants in considering these through providing a copy of the easy-to-read DEEP guide beforehand, it appears further support may have been needed. In future studies, having interview questions explicitly addressing key aspects, such as respect, equality, dignity and autonomy, rather than a general question, may be more productive.

Conclusions

This study adds to the evidence base on the quality of life and well-being of people living with advanced dementia. The study provides evidence of signs of well-being of people living with advanced dementia in care home settings. In addition, the research highlights views of family members who maintain a high level of involvement, once their family member moved into a care home. Moreover, the study demonstrates the benefits of the triangle of care, the advantages of having a positive relationship between care staff and families and the impact this has on the resident. Based on these findings, to deliver person-centred care in advanced dementia, we recommend tailoring care towards individuals' needs and preferences, as opposed to expecting individuals to fit in with the routines and practices of the service. This requires close collaboration and a good relationship with family members and adequate staffing so that individual preferences can be respected. Whilst our study has highlighted the importance of family involvement in care homes, not all residents will have families that are involved in their care. This presents a challenge for those supporting people living with advanced dementia in care homes. The settings in this particular project (households) referred to as 'individual communities' enabled family members to form relationships with each other and with residents on the households. Consequently, individuals who did not have their own family member were often involved, at least passively, with visitors being mindful of such residents. Staff should be aware that these residents will rely even more on them for social interaction and activity and that they may be at increased risk of becoming socially isolated. The British Geriatrics Society (BGS, 2011), state that care home staff become both advocates and facilitators, and should be equipped with the skills for that role. However, numerous professionals are now linked with the role of advocacy, leading to an unclear view of what it entails exactly and who is best suited to this position (Schwartz, 2002). Despite numerous views of who is nominated for this role, Schwartz (2002) states the relationship the care-worker has with residents is one of care, where best interests of the individual are at the core of care practices and decisions. If this were the case, then arguably the individual should not need anyone else to ensure this on their behalf, but regularly reported lapses in the care system suggest this may not be sufficient in all instances.

The study highlights that human rights are not widely discussed within the homes and information regarding them is not readily available. The study identifies a gap in the current knowledge and some confusion of what human rights are and their application in care homes. The lack of knowledge regarding human rights within advanced dementia needs to be addressed to support a change in the current culture and include the aspirations of people affected by dementia (DEEP, 2016). As a way forward towards integrating human rights–based practice in advanced dementia care with person-centred care, we recommend small but effective steps, returning to basic principles. Families and staff need to ask questions such as ‘What’s important to the individual here? Have they been given the opportunity to make their own choice as best as they can? If I’m making a decision on their behalf, is it within their best interests?’ Rights can then be understood at a human level, rather than through lengthy documents, ensuring individual needs are met, rather than simply avoiding harm.

Chapter 5: The Quality of life and well-being of individuals living with advanced dementia; resident, relative and staff perspectives: Two case studies

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Introduction

Quality of life (QoL) has become increasingly recognised as an important goal in dementia care, underpinning healthcare policies and strategies. The latest Dementia Action Plan for Wales 2018-2022, p25 states that care homes need to be considered as an individual's home, and people have the right to 'live well'. As discussed in Chapter 1, according to the World Health Organisation (1995, p1) QoL is reliant on "the individual's perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards". There are now a number of QoL measures that have been used to enable people with dementia to indicate their subjective view of their QoL, but increasing cognitive impairment may make it challenging for individuals to self-report their own QoL (Algar et al., 2016; Bowling et al., 2015; Logsdon et al., 2002). In advanced dementia, proxy-reports are an alternative, completed by family carers or by care-workers (Conde-Sala et al., 2010), consisting of direct observations or questionnaires or a mixture of both (Missotten et al., 2016). However, these beg the question as to what constitutes QoL in advanced dementia?

In Chapter 1, Lawton's (2004) framework for QoL was introduced, combining the subjective, such as psychological well-being, with objective approaches such as the environment and behavioural competence (Netuveli & Blane, 2008). Disentangling the terms 'well-being' and QoL has proved challenging and they are often used interchangeably. In terms of well-being, Chapter 1 set out Ryff's (1995) general model of psychological well-being (Table 1.1), indicating that psychological well-being involves much more than happiness. Although aspects such as self-growth, autonomy and sense of purpose may be more difficult to ascertain or even envisage in the context of severe impairments in cognition and communication, Kitwood's (1992) summary of indicators of well-being in people living with dementia as being characterised by feelings of worth, hope and agency, and by social confidence gives some potential parallels. Many of the indicators listed in Table 1.2 can be observed in people living with advanced dementia, despite limited communication abilities.

In addition to QoL and well-being, Chapter 1 also introduced human rights as an alternative but potentially complementary perspective, with the 'FREIDA' principles (see Table 1.3) having proven useful in dementia care (Butchard & Kinderman, 2019). Dignity and Respect have long been associated with good quality dementia care, and Identity has emerged as of special relevance in dementia, where the person experiences threats to their sense of identity and personhood through the development of their condition and, importantly, the reaction of society to it. The human rights perspective is also set within a legal and ethical framework (Kelly & Innes, 2013), making it possible to challenge unfair and inequitable treatment of people living with dementia, including those with advanced dementia living in care homes. It sets a standard for care, and a basis for raising such standards.

As dementia progresses, many individuals require care home placement, and here purposely designed and adapted environments, providing relaxation and opportunities for personal contact can enhance QoL (Bauer et al., 2015). However, placement means leaving their family home, perhaps shared with loved ones, for a communal environment shared with strangers. This is also a transition for families, where they have been providing the care previously. Attention to the involvement of families, for example, through an understanding of the triangle of care, with family and care home staff working together has led to better outcomes for care recipients, families and care professionals (Royal College of Nursing, 2014).

Aims

The aim of this research was to investigate the QoL and well-being of individuals living with advanced dementia in the care home sector. We aimed to explore residents' lived experiences in the care homes, their relatives' and their key staff members' perspectives of their quality of life and well-being and how this is expressed. Further, we aimed to investigate how human rights of residents are upheld and how family members and staff members deal with surrogate decision-making. These aims are pursued through two in-depth case studies of care home residents, Graham and Martha (pseudonyms) living with advanced dementia. We explore how helpful the different approaches to understanding QoL, well-being and human rights in advanced dementia are in practice and identify features that may be helpful in supporting these important outcomes.

Method

The research took place across two specialised dementia care homes, operated by an independent care home company in North Wales. The homes are divided into households of 8 to 12 residents, with each household providing care to individuals in different stages of dementia. Family members visit the households daily and an activities co-ordinator organises some activities. The study employed a mixed method approach, with data being collected through observations of residents in public areas of the care home, during 30-minute observations on 5 occasions. Further, in-depth, semi-structured interviews with care staff and families of residents were conducted alongside quantitative measures. These measures were selected based on the review of measures presented in Chapter 2. The quality of life in late-stage dementia scale (QUALID) was completed independently by a family member and by a staff member. It comprises 11 items reflecting positive and negative components of observable mood and behaviour. Each item is rated on a five-point scale with *lower* scores indicating a higher QoL (Weiner et al., 2016). The AwareCare tool (Clare et al., 2012), is an observational tool, evaluating signs of awareness of residents living with advanced dementia, examining responsiveness to a variety of triggers in the social environment. Consent was obtained from relatives and care staff, but as the residents were unable to give consent, a personal consultee was approached to advise on their inclusion in the study. Here we focus on one resident from each home, from the ten who participated. The two cases were selected as they are living with advanced dementia within the same care home organisation, at two different homes. The cases focus attention on two very different individuals, with their own unique personalities and ways of expressing their happiness, affection, humour and distress.

Case study one: Graham

Graham was 88, had been diagnosed with dementia 6 years ago, living at the care home for twelve months. He was immobile, and it was usually late morning before he was brought to join the other residents in the lounge. During observation he appeared busy, often picking up objects to explore with his eyes and hands. When people stopped to interact with Graham, he was delighted, waving at them and blowing raspberries, eliciting a laugh in response. When there was no response, he proceeded to throw objects from his table; this brought a staff-member quickly over to him asking "*Graham, what have you done?*". Graham laughed, blew raspberries and pointed at her, blowing kisses and tapping on the side of his chair, apparently delighted. The majority of Graham's communication methods were non-verbal, and he displayed 'happy behavior', which consisted of smiling, laughing and blowing kisses when engaging with others (Astell & Ellis, 2006). However, Graham's attempts to contribute socially were not always appreciated, as there was a possibility this could affect others on the household. At one point, Graham poured his drink onto the floor beside him and proceeded to bang his cup on the side of his chair.

The researcher used the ‘Talking Mats’ communication tool (Murphy & Oliver, 2013) with Graham, presented on a tablet. He was very interested in the tablet itself but made several attempts to move the cards across the screen into their different categories. He attempted to pick up the tablet to inspect the screen closely and nodded in response when the screen lit up on being touched. During the AwareCare tool assessment Graham reached out to hold the researcher’s hands and shook them playfully, saying “wooo” and laughing loudly when the researcher laughed. He reached out and pinched the researcher’s nose and gasped when she laughed; he gestured to his own nose with his hand and when the research touched the tip of his nose, he smiled, nodded and clapped.

Graham’s wife, Lorna, arrived daily around lunch-time, bringing in different magazines and newspapers and reading them to him. He was a big sportsman and she flicked through to the sports pages with him. Graham was observed to study the newspaper and run his fingers across the photos and sometimes laughed at Lorna whilst she read. He pulled on the bottom of the newspaper and laughed when Lorna told him off playfully.

Lorna felt that becoming immobile had impacted on Graham’s QoL and human rights. He was previously very active, sociable and enjoyed going out every day. His mobility had deteriorated following a fall and he had not been encouraged to walk during a 3-month hospital stay, before coming to the current care home. She explained that he would often respond with ‘No’, irrespective of the request, and this had been interpreted as a refusal; she felt that with encouragement and support he could have remained mobile. When Graham moved into the care home, Lorna was keen for Graham to receive physiotherapy, but the home considered that his condition was now too advanced to benefit. From the home’s perspective, not to take his refusal at face value would be to detract from his human rights, but Lorna felt that this was not within his best interests, leading to some tension, but she felt she had to accept the situation.

Lorna explained Graham’s attempts to interact:

“*oh he likes attention you know*”, *“he’s known to throw objects at times, he’s easy to care for, but like everyone, he has his moments”.*

Lorna enjoyed spending time with Graham at the home, but found it difficult:

“*I just don’t see him the same as the others you know. He’s different isn’t he”?*

*S*he observed other residents sleeping often, whilst Graham would be wide awake, calling out to others, desperate to interact. This made leaving him even more difficult.

Stephanie, a Senior Care Assistant, explained that when Graham throws objects, it is not aggressive behaviour, she said:

“you know he’ll throw and he smiles, you can tell, he’s got that cheeky twinkle in his eye”.

To Stephanie it was his way of saying, “*look at me”,* drawing attention to himself and initiating interaction with others, perhaps reducing boredom.

Stephanie had also noticed that later in the day, around tea-time, when families had left, it was quiet on the household, with staff assisting residents to eat. At these times, while Graham was alone, he would throw his food, drink and any object nearby and become agitated. Stephanie felt that Graham was responding to a lack of stimulation in the environment

“*it’s too quiet in here, it seems and maybe there’s not enough going on tea time”.*

The staff recognised Graham’s actions at tea-time, such as throwing, as an attempt to initiate interaction with others. Accordingly, the staff kept food aside, until they could sit with Graham and encourage him to eat independently. Making adjustments such as these allows the enjoyment of meal times, providing physical benefits and adding to overall QoL (Biernaki & Barratt, 2001); nourishment is important for QoL, physically and psychologically. The removal of strict routines, allowing people to eat out of the ‘set time zones’ and responding to preferences, allows individuals to eat at preferred times, and in Graham’s case enabled him to eat independently.

In summary, although Graham had little verbal communication, he used non-verbal communication extensively and with the support of his wife and the understanding of staff, his personhood was evident. On the QUALID scale, his wife and care staff rated his current QoL at the same level (21), despite Lorna’s concern about no attempt being made to reduce his immobility. This is similar to the mean scores for care home residents with advanced dementia reported by Clare et al. (2014).

Case study two: Martha

Martha was 86 and had been diagnosed with dementia 4 years ago, living at the care home for the past 14 months. Her first language is Welsh. Martha was observed sitting with others in the living room smiling broadly when greeted by staff members. Martha initiated conversation with others, often mumbling but occasionally pronounced clear words. Martha called out "*hurry*", "*come on en*" and "*bugger you*" at the care staff and residents. At a meal-time, Martha gestured at others nearby her to eat, tapping the table and pointing towards their plates and pushing their plates towards them, taking on a mothering role. However, on other occasions, Martha's behaviour changed significantly and she appeared distressed. She was observed shouting in response to others or sitting alone in a separate room, with her arms folded and her head in her chest. During this time, Martha would refuse assistance from the care staff, shouting "*shoo, shoo*" and throwing her hands up in the air. Staff attributed these changes to recurrent urine infections.

The researcher, a Welsh speaker, used the 'Talking Mats' communication tool (Murphy & Oliver, 2013) with Martha, presented on a tablet. Initially she was very interested in the screen, inspecting it closely, leaning over the screen. Martha let the researcher guide her hand over the screen to place different cards in different places "ooo" she said and laughed. During the AwareCare assessment Martha took great interest in personal objects from her home that were presented to her. Martha would point at people in photographs and nod, feel and touch her soft toys, cushions and sometimes responded verbally, "ahh" "yes, yes" in Welsh. Martha would respond most times to her name being called, she would turn her head and explore the room, and shrug her shoulders.

Martha's family visited daily, speaking with Martha in Welsh. During a Welsh conversation, with her daughter Jo, she was observed to sit up, smiling broadly, her eyes open wide, fully immersed in the interaction. She made direct eye contact and nodded whilst Jo spoke with her, reciprocating vocally and non-vocally and reciting family members names.

Jo explained that care staff had taken time to understand Martha's personal history:

"*the staff know her you know like they can walk in now and tell you, how she is, what kind of person she is, they do know her, that helps us as well".*

Jo laughingly described her mother's character:

"what she said went, you wouldn't dare disagree".

She enjoyed seeing aspects of her personality still evident, although not always easy for the staff. Jo discussed:

"it is important for us to make the most of it now while she is chatty like this, because there will come a time won't there where there will be no communication".

Although Jo had reservations about Martha living at the care home, she talked about visiting and explained:

"It's nice to see her in good spirits, displaying ways she used to be. The way she was at home .. mischievous".

Jo considered that the care her mother receives at the home contributed to their family's well-being and that the relationship with the care staff has made the journey easier for them.

Martha's staff nurse, Gaynor, described Martha as a charming lady, compliant with care, who eats and drinks when physically well. Martha was vulnerable to urine infections, and during these times may be awake at night, refusing medication, food and fluids, inevitably prolonging her ill-being. Gaynor explained that at these times:

"She becomes frustrated, as a result of being unable to verbalise how she's feeling".

Gaynor felt Martha's family involvement was fundamental to her QoL, they were able to speak with her in her first language and encourage her to take her medications, eat and drink.

Overall, it is clear that Martha was able to communicate her feelings through vocal and non-vocal behaviours and was able to verbalise more when with a person who could speak Welsh, her first language. Having a close family nearby, especially when Martha was unwell, was important to her well-being. On the QUALID scale Martha's daughter rated her QoL much more positively (17) than did staff (41). Martha's daughter expressed how important it was to see her mother as the individual she had always been, but this could be difficult for the staff, especially with her recurrent physical problems, which may have influenced the staff view of her QoL being less good.

Discussion

If we consider Graham and Martha from the perspective of Ryff's well-being framework (Table 1.1), it is evident that both are seeking to exert control over their environment through their behaviour (environmental mastery) and that positive relationships are of prime importance. Acceptance, sense of purpose and self-growth are more difficult to judge. In terms of human rights, *identity* emerges most strongly as a positive factor for both, with Graham's right to *autonomy* being reduced by his immobility. The relative lack of Welsh-speakers amongst the care home staff may be viewed as reflecting a lack of *fairness* in meeting Martha's needs, but also impacting on her *identity* as a Welsh-speaker. In Kitwood's terms (see Table 1.2), both Graham and Martha show *agency*. Graham throws objects to achieve a response; Martha encourages her fellow-residents to eat. They are both *socially confident*, especially in relation to their relatives. Martha may show less *hope and self-worth* when she has a urine infection and is unwell and becomes distressed. Graham's *self-worth* is evident in the warmth of his relating, and lack of distress. Both demonstrated a number of Kitwood's indicators of well-being: e.g. initiating social contact, humour, self –expression, affectional warmth, social sensitivity and the ability to express a range of emotions. Kitwood's (1997b) personhood theory suggests that personhood does not lie within the individual, but is supported by the presence of others, and this is evident for both Martha and Graham, whose individual personalities remain evident to family members and to staff who made the effort to get to know them well.

In addition to these perspectives on QoL and well-being, the unmet needs model of Cohen-Mansfield et al. (2007; 2015) is also relevant. People with advanced dementia may have decreased ability to communicate their needs, which are accordingly unrecognised and unmet. For Graham, calling out and throwing may act to alleviate boredom, a way of communicating his need for interaction and affirmation. For Martha, her distress may be communicating her discomfort, pain and illness.

Learning Outcomes

Individuals living with advanced dementia may have complex needs that require intervention. Advance care planning tends to focus on resuscitation and death and advance directives on individual daily care preferences are less common (Mitchell, 2004). Spending more time discussing advance care plans has been linked with higher family care satisfaction (Mitchell, 2004). Lorna clearly expressed her feelings about Graham's immobility and the lack of intervention he received. There is a negative perception, that individuals at this stage of their dementia journey do not have restorative potential. Despite these views, promoting and maintaining resident functional abilities for as long as possible contributes to QoL and decreased caregiver burden (Sandberg et al. 2002).

Advance care planning with the family can identify factors about the resident and provide deeper understanding of the individual. Martha’s first language was Welsh and she had rarely spoken English. It was clear that Martha had a better understanding when addressed in her first language. At times, Gaynor explained, Martha could be non-compliant, and they had the benefit of having her daughters, who spoke with her in Welsh, which encouraged her to communicate, and take her medication. Although Martha may be unable to recognize her family members, having the opportunity to converse in Welsh supported her sense of safety, familiarity and comfort, which contributed to her overall QoL (Martin et al., 2018). Martha’s difficulty in communicating in her second language, coupled with her illness, may have added to her psychological distress, impacting her well-being (Hamilton, 2008).

Language goes beyond the spoken word, as was evident in much of Graham’s and Martha’s daily behaviour. Discussing Graham’s refusal to comply with physiotherapy in hospital, Lorna expressed that his ‘no’ was not a refusal, but his way of contributing to the conversation. Considering the congruence between an individual’s behaviour and their verbal communication could improve decision making. Numerous research studies have placed emphasis on non-verbal behavioural cues, often supplementing verbalisation. Not only in dementia, non-vocal behaviours are used across a lifetime forming part of the individual’s identity. They are an important form of communicating and comfort for families in the absence of verbal communication (Hamilton, 2008). Ignatieff (1999) wrote the following about his mother:

“It (my mother’s disease) changed my view of what a person is.... It taught me, to be less sentimental about memory as a carrier of human continuity. My mother had no memory whatever, but she was the same person.”

Jo also emphasised the importance of cherishing the moments she has with her mother, as she is now.

Conclusions

The case studies of Graham and Martha add to the evidence base on quality of life and well-being of people living with advanced dementia, an important area, which has received little attention or innovation in recent years. Through these case studies we have drawn on residents’ daily lived experiences and the viewpoint of relatives and staff members, to further our understanding of quality of life and well-being of residents living with advanced dementia. Comparing a variety of perspectives, Kitwood’s model is especially helpful in describing the experience of relatives and staff; despite limited verbal communication, the person remains, and with the support of others can experience well-being and QoL.

Chapter 6: Advanced dementia in care homes: a mixed-methods, multiple perspective, collective case study evaluation – I: quantitative findings

"I'm not bothered about the décor, it's been designed for people with dementia, brilliant. It is very clean, but we don't know what the staff are like, what they are going to be like. Eventually she came, she has been here since, it took me a long time to get used to (home) and trust (home), I do trust them now, but even so Sian. You have to be there to exert that pressure, no matter how good they are. But I feel for people who don't have visitors here, there's nobody watching over them you know? It's all very well looking at the people who have people, but that's where you need the work Sian, with the ones that don't have"
(Husband participant, Study 1)

Introduction

When a person moves into a care home, following in some cases a trial period, the care home becomes their permanent place of residence, their home. As with our daily lives outside of care home placement, the environment in which we spend our time, and the quality of our relationships and interactions within the environment, will naturally and inevitably impact on our quality of life (Jing et al., 2016). The majority of care home residents have dementia, as well as other health issues, and many – especially those with advanced dementia - are approaching the end of life. Understanding the influence of the care home culture and environment and the quality of end-of-life care on the lives and well-being of residents with advanced dementia is a crucial step towards improving care provision.

Despite care homes providing invaluable healthcare for older people, with varied and increasingly complex care needs, this sector is often the most overlooked and underfunded. Figures now show care homes provide more beds than NHS hospitals, which highlights the increasing need for non-acute care, as people are growing older with care needs (Care Quality Commission, 2019). Care homes are providing care for older people with complex care needs, with one of the most common conditions leading to this complexity being dementia (Mitchell and Agnelli, 2015). According to the Alzheimer's Society (2019) up to 80 per cent of UK care home residents are living with dementia or have memory problems. Additional conditions leading to complex needs prevalent in care homes include progressive neurological conditions, cardiovascular disease and diabetes (Mitchell & Twycross, 2016). Furthermore, care home settings have the challenge of providing personalised, individualised care and support in a communal setting and must find the balance between risk-taking and safeguarding, protecting the individual's right to autonomy and independence (Evans et al., 2018).

Labelled as 'social care', despite providing support for health needs alongside social needs, this sector is undoubtedly the poor relation of the NHS. The importance of care homes and the services they provide is not always considered, or value given to the contribution of the care staff and nurses providing care for the residents. Care homes are confronted with complex ethical dilemmas. Providing high quality person-centred care is costly and yet there is widespread agreement that social care has been underfunded for many years, with successive governments unable to grasp the nettle of how to address the issue. Care staff themselves are often working in less than ideal conditions. They come up against daily complex situations, such as personal care scenarios, where they may be overstretched and do not have the opportunity for learning and development (Killett et al., 2016); they are not well paid and feel unsupported and undervalued (Brooker & Kitwood, 2019).

Although care staff are eager to learn and progress, according to a review by Spilsbury and colleagues (2015), there are significant barriers to accessing learning/development, including; low staff levels, with not enough staff available to cover for the staff attending the training; expectations placed on staff to attend courses during their own time (unpaid): and difficulties in accessing specialised training courses. Also, as highlighted in previous research (Cousins et al., 2016) typically, care homes, unlike the NHS, do not have their own specific or designated training and development departments. Therefore, staff may undertake the care home's induction as part of their formal training, but may not have other opportunities for further learning, with external courses considered too costly by the care home providers (Cousins et al., 2016).

Despite this context of underinvestment in care homes and training, individuals working in care homes are expected to undertake a multifaceted role. In addition to providing care for individuals with varied conditions, they provide rehabilitation and palliative care as well as respond to emergency situations (Mitchell, 2015). Furthermore, given the prevalence of people living with dementia in care homes, the staff must also face a number of challenges including:

- Maintaining quality of life for people with dementia, in the context of a condition that is typically progressive with no curative treatment.
- Maintaining and promoting human rights in a communal living context situation where autonomy and individual decision-making are often compromised.

These challenges are made more difficult by high levels of staff turnover, with understaffing in care homes being a major catalyst of many difficulties. High staff turnover is likely to lead to lack of continuity of care for care home residents. Further, high staff turnover places a higher burden on the remaining members of staff, potentially causing staff strain and burnout, and places additional pressure on the homes, with continuous recruitment and induction activities required. (Cousins et al., 2016).

Providing quality care to people in the advanced stages of dementia is challenging (Harris, 2007; Küpper & Hughes, 2011) and can place high physical and emotional demands on all those providing care. The World Health Organisation considers dementia care a priority public health issue and emphasises the need for care and support of caregivers (World Health Organization, 2012). In addition to working with behavioural, physical, and cognitive complexities of dementia, professional caregivers in care homes have an important role in communicating with families and supporting them as proxy decision makers (Hennings et al., 2010; Hertzberg & Ekman, 2000; Sandberg & Nolan, 2002; Maas et al., 2004). Despite their family member making a transition into care home placement, this does not end their role as a carer, rather the role has changed. Many individuals living with advanced dementia cannot monitor their own care, and they depend on oversight from their family members as care proxies. Research investigating advanced dementia in care homes from a family carer's perspective is limited, despite families finding themselves in situations where they are expected to make end of life decisions, and where they often experience anticipated loss of their relative and have their own personal needs (Hennings et al., 2010).

Literature commonly exists for family carers in home settings, focusing on burden, coping (Diwan et al., 2004; Mausbach et al., 2007; Sanders, 2008) and eventually transition into care home placement (Gaugler 2005; Gaugler 2007; Rudd et al., 1999). Where family experiences have been sought, it has centred on QoL of the resident, 'good death' and bereavement (Bosek et al., 2003; Robinson, 2008; Waldrop & Kirkendall, 2009). Rarely have family members' views in their own right been elicited, or their experiences of their relatives living with a terminal illness in a care homes, or their experiences at this point of strain, personal feelings and well-being (Hennings et al., 2010).

Less is known about the factors relating to strain and well-being of professional caregivers in care homes, for people living specifically with advanced dementia (Costello et al., 2019; Edberg et al., 2008; Pitfield et al., 2011). A recent systematic review and meta-analysis identified moderate levels of emotional exhaustion and lower mental health quality of life in staff in long-term care facilities for people with dementia (Costello, et al., 2019). Risk factors included the presence of challenging behaviour, feeling unsupported and a poor environment. As the numbers of people living with dementia in the later stages in care homes continue to rise, it is important to understand the needs of care staff for support and guidance, and how best to foster relationships between families and care homes that result in the best outcomes for care home residents with advanced dementia.

Aims

In Study 1, reported in Chapters 4 and 5 of this thesis, based in two care homes within the same organisation, with broadly similar characteristics and management, I found that relatives who visited daily worked collaboratively with direct care staff to maintain the quality of life of their residents and act as proxy decision makers. The limited discussion of residents’ human rights focused on avoidance of abuse rather than on promoting well-being. Accordingly, in order to build on the earlier study to extend its scope and breadth of findings on quality of life and well-being in advanced dementia, in this study I aimed to:

1) Increase the range of care home contexts studied by including a care home operated by a different organisation, as well as a home recently taken over by the original organisation, increasing the range of management styles and ways of working.
2) In recognition that many residents did not have the involvement of a relative or friend on a daily basis, to include relatives / friends less frequently in contact.
3) To explore human rights considerations in more detail than proved possible in Study 1, by an even greater focus on this in the fieldwork undertaken.
4) To consider in more detail well-being of staff and relatives and satisfaction with care, using questionnaires to augment interview data.

In the remainder of this chapter, the characteristics of the two care homes recruited for Study 2 are described, before reporting on and discussing the questionnaire data on quality of life, well-being and satisfaction with care. The subsequent chapter reports on the qualitative work undertaken in the two homes.

Methods

Design

This study builds on the previous work reported earlier in the thesis, using an instrumental collective case-study design as set out in Chapter 3 (Baxter & Jack, 2008; Stake, 2005), with multiple cases purposively selected to provide a broader range of experiences, leading to a fuller understanding of the issues (Crowe et al., 2011; Stake, 2005). The data collected comprised qualitative interviews with a number of relatives of residents and with staff in the participating care homes and a number of questionnaires completed with the relatives and staff. It is important that in collective case studies each individual case is described in detail, with flexible approaches to data collection, before exploring similarities and differences across the cases (Crowe et al., 2001).

In this chapter, demographic and questionnaire data are presented and analysed, in order to provide such a detailed description of each of the cases i.e. the care homes, and to assist in understanding factors associated with well-being and satisfaction of relatives and staff. The qualitative data analysis will then be presented in Chapter 7, analysed using Stake's (2005) collective case study cross-case analysis approach, building on the quantitative data presented in the current chapter for a fuller understanding of each case.

Settings

The research took place in two individual care homes, each serving as a 'case'.

Care Home 1

Care Home 1, during the period of data collection, had recently come under new management (by the same organisation that operated the two care homes previously studied), having been in administration for a number of years, with a number of staff having been made redundant, and the home facing potential closure. It had a chequered history, involving concerns over quality of care under previous proprietors. In contrast to the two homes in Study 1 from the same organisation, Care Home 1 had not been designed specifically to offer dementia care and indeed had a challenging physical layout in relation to dementia care. Under new management, proposals were put forward to invest significantly, to make changes to the current layout of the property, with the specific aim of offering a dementia specialised unit, comprising of three separate households, supporting people at different stages of the illness. During the data collection period, the home had been undertaking extensive architectural and building work resulting in significant changes and disruption at times to working and living areas. The home is a purpose-built care home, a three-storey building, offering 77 bedrooms, situated in a rural village, offering residential, nursing and dementia care, with the majority of individuals receiving nursing care. The home has various community lounges, and living spaces, with dining tables, where residents were encouraged to eat together, as well as quieter spaces, offering views of the surrounding gardens, which could be accessed from the living areas.

Care Home 2

Care Home 2, the setting for the second case study, had expressed an interest in taking part in research and was purposively selected as it offered a clearly different layout and environment from Care Home 1 and from the homes included in Study 1. It is a registered nursing home, privately owned by a single proprietor, of thirty years. The home accommodates up to 52 people, providing single bedrooms, with a high proportion of residents requiring full-time nursing care. The home is a large building, which is situated in a residential area. The home comprises an open plan living area, with dining tables, where residents would eat together. The communal living area, is where the residents partake in arranged activities and access the ‘award winning’ gardens. Central to the open living area is access to the kitchen and also home to the care manager’s office and the main reception. Families would often visit residents in the lounge and were invited for dinner and any activities that were arranged. Residents were encouraged to bring in their personalised belongings from home to the communal living area, to support residents feeling at home.

Ethical Issues

Ethical approval was received from the University Healthcare and Medical Sciences Academic Ethics committee and the North Wales Research Ethics Committee (17/WA0015), November 20th, 2017. Eligible participants were approached by care home managers and the researcher. Information leaflets and posters were available throughout the home. The potential participants were given information sheets along with consent forms in Welsh or English, depending on preference, detailing the aims and procedures of the study. Following discussion of the project with the researcher, written consent was sought from relatives and staff members prior to interviews. All participants provided consent to take part in the interview, including consent for audio recording of the interviews.

Participants

Potential participants were advised their involvement was voluntary, and if they chose not to participate, this decision was fully respected by the researcher. Family members of residents living with advanced dementia (operationally defined as CDR 2-3; FAST 6-7 see below) were identified by the care home managers and senior care staff and invited to participate, with one family member per resident taking part. A family member from all residents meeting the criteria for advanced dementia was approached.

In Care Home 1, eight relatives took part out of a possible 23. Where relatives were not local to the area, a member of the reception staff informed relatives of the project. Following this, relatives received an invitation to participate in the project, in the form of a letter. Seven relatives, who received invitations by post, did not respond to the invitation. Three family members declined to take part, based on their own health status. Four relatives declined to take part due to their dissatisfaction with the home coming under the auspices of this specific care home organisation. One relative consented to participate, but then changed her mind, based on an ongoing dispute with the care home.

In Care Home 2, six out of a possible eight family members took part, with one relative agreeing to participate, but the researcher was unable to make contact with the individual by telephone or at the home to arrange interview. One relative declined, based on being satisfied with the home, feeling they did not have anything further to contribute.

Family members took part in interviews and completed questionnaires regarding their relative. Relatives filled out the questionnaires with the researcher. Staff members were recruited to provide information about the same resident, during interview and questionnaires. Care staff members had to have good knowledge of the resident and their daily lived experiences. Where care staff had time, they filled out questionnaires with the researcher, but a number of staff participants returned the questionnaires to the researcher subsequently.

Measures

Relating to people with dementia

To assess the eligibility of residents living with dementia, the Clinical Dementia Rating scale (CDR; Morris, 1997) was used to assess the severity of dementia. The CDR assessment was rated by the researcher from information provided by care staff. Staff were able to indicate possible residents who would meet the criteria (CDR 2-3; FAST 6-7). The CDR scale measures stages and severity of dementia with 0 indicating no impairment and stages 0.5, 1, 2 and 3 indicating questionable dementia, mild, moderate, and severe dementia, respectively. Care staff also completed the Functional Assessment Staging (FAST; Sclan & Reisberg, 1992) for each possible resident. The FAST procedure encompasses the progression of Alzheimer’s disease in 7 stages. The FAST stages begin at stage 1 (normal) to stage 7 (severe dementia). Residents meeting the criteria for advanced dementia in this study were expected to be at stage 6 or 7.

To measure functional status of the residents, the Katz Index of Independence in Activities of Daily Living (Katz ADL; Wallace & Shelkey, 2007), was used. The tool is commonly used by clinicians to measure an individual’s ability to perform activities of daily living independently and used to plan care accordingly. The Index scores ability and performance in six functions; bathing, dressing, toileting, transferring, continence, and feeding. Individuals are scored yes/no for independence in each of the six functions. A total score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment (Shelkey, & Wallace, 2012).

The Quality of Life in Late-Stage Dementia Scale (QUALID; Weiner et al., 2000) was used to evaluate residents' quality of life. The QUALID is completed as a proxy assessment, and in this study was completed independently by staff members and relatives. The measure consists of 11 items, comprising both positive and negative dimensions of observable mood and behaviours, thought to be indicative of QoL in late-stage dementia. The items are rated by frequency of occurrence on a five-step scale, and scores range from 11 to 55, with, unusually, a higher score indicating a *lower* QoL.

Relating to relatives

To evaluate relatives' satisfaction with care, relatives were asked to rate their overall satisfaction with the care provided to their resident, using a 5-point Likert scale, designed for the project, with items; 1 Very Dissatisfied, 2 Dissatisfied, 3 Neither Satisfied or Dissatisfied, 4 Satisfied, 5 Very Satisfied.

In addition, the Scales of Evaluation of End-of-Life Care in Dementia (SWC-EOLD) (Volicer et al., 2001) were used. This is a proxy administered scale to evaluate satisfaction of care and experiences of people with advanced dementia at the end of life. Responses are given by participants on a four-point scale 'strongly agree' (4) to 'strongly disagree' (1). The scale assesses satisfaction with care during the prior 90 days and has often been used retrospectively after the death of the person with dementia. The questionnaire items address decision-making, communication with health care professionals, understanding the resident's condition, and the resident's medical and nursing care. The published scale has 10 items, but one item was removed for this study, as it relates to the person's death: 'I feel that my care recipient needed better medical care at the end of his or her life'. Total scores on the relative-completed nine-item SWC-EOLD were calculated, reverse scoring items 2 and 5. Possible scores could range from 9 to 36.

To assess strain experienced by family members, relatives completed the Zarit Burden Interview (ZBI; Bédard et al., 2001), the most widely used instrument for assessing personal and role-related strain experienced by the family carers of persons with dementia (Bachner &

O'Rourke, 2007; Bédard et al., 2000). The measure consists of 22 self-report items, which the respondent is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). Total scores range from 0 (low burden) to 88 (high burden).

Relating to staff members

Staff well-being was evaluated using the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007). This scale comprises 14 items that relate to an individual's state of mental well-being (thoughts and feelings) in the previous two weeks. Responses are given on a 5-point scale ranging from 'none of the time' to 'all of the time', in which all items are worded positively. The overall score for the WEMWBS is calculated by totalling the scores for each item, with equal weights. A higher WEMWBS score therefore indicates a higher level of mental well-being.

Results

Key characteristics of the two homes (see Table 6.1)

Care Home 1 (CH1) is the larger of the two homes, with a greater proportion of residents with advanced dementia. As with many care homes, the absence of a specific 'dementia' registration category for Care Home 2 (CH2) did not indicate that a large proportion of the residents did not have some degree of dementia. CH2 had a higher staff to resident ratio and had many fewer lounge areas to cover. Staff in CH1 did not wear uniforms, whereas those in CH2 did so. Despite the smaller number of residents in CH2, there were 2 Activity Coordinators, compared to 1 in CH1.

Characteristics of participating relatives and staff and differences between homes

Descriptive details of the residents and participating relatives and staff members who contributed are provided in Table 6.2.

Relatives: eight relatives (six female, two male) participated from CH1 and six (four female, two male) from CH2. In CH1, 5 of the participating relatives were daughters, 2 were sons and 1 a daughter-in-law of the resident. In CH2, 4 relatives were daughters and 2 were husbands of the resident. The relatives' mean age for CH1 was 59.8 (*SD* 4.40) and for CH2 63.2 (*SD* 12.38); this difference was not significant. On average, relatives visited in CH1 2.84 times a week (*SD* 2.67); in CH2 the mean number of visits per week was 3.83 (*SD* 1.60); this difference was not significant (t=-0.87; p=0.404).

Table 6.1: Characteristics of the care homes at time of data collection

	Care Home 1	**Care Home 2**
Number of residents	64	52
Number of residents with advanced dementia	23	8
Staff-resident ratio	1 to 3 or 4	1 to 2
Registered care categories with regulator Care Inspectorate Wales	Dementia Old Age Physical Disability Sensory Impairment	Old Age Physical Disability Sensory Impairment
Number of units / households	0	0
Floors	3	2
Communal lounges	5	1
Activity Co-coordinators	1	2
Capacity	New residents arriving	Full capacity
Uniform	Non-uniform policy	Uniform policy

Staff: The mean age of the participating staff in CH1 was 38.9 (*SD* 15.19) whereas in CH2 the mean age was significantly older at 52.7 (*SD* 6.06) (t=2.33; p=0.043). Staff in CH1 comprised 1 registered nurse, 4 senior care attendants and 3 care attendants; in CH2, 2 nurses and 4 care attendants participated. Staff in CH1 had worked in the home for an average of 1.90 years (*SD* 1.11), whereas staff in CH2 had a significantly longer duration of employment in the home (*M* 10.78 years, *SD* 10.69) (Mann-Whitney U-test, p=0.001; median Care Home 1: 2 years; Care Home 2: 4.5 years). All the staff from CH2 were female, six of the eight from CH1 were female.

Residents: Three of the eight residents in CH1 were male and one out of the six in CH2 was male. The mean age of the residents was 84.1 (*SD* 7.14) for CH1 and 78.8 (*SD* 11.34) for CH2, but this difference was not significant. Residents in CH1 had been resident in the home

Table 6. 2. Summary of demographics and questionnaire scores (mean and standard deviation) for Care Homes 1 and 2.

Differences tested for significance with independent samples t-test except where indicated.

Significant differences indicated in bold.

		Care Home 1	Care Home 2	
Residents	Age	84.1 (7.14)	78.8 (11.34)	t=1.00; p=0.345
	Gender	5F 3M	5F 1M	
	Duration of stay in care home (months)	15.6 (10.08)	21.5 (14.0)	t=0.92; p=0.378
	Number of visits received per week	2.84 (2.67)	3.83 (1.60)	t=0.87; p=0.404
	QUALID (Relative rating)	19.38 (5.34)	18.5 (2.26)	t=0.42; p=0.686
	QUALID (Staff rating)	22.0 (5.4)	25.3 (4.18)	t= 1.25; p=0.234
Relatives	Age	59.8 (4.40)	63.2 (12.38)	t=0.65; p=0.542
	Gender	6F 2M	4F 2M	
	Relationship to resident	5 daughters 2 sons 1 daughter-in-law	4 daughters 2 husbands	
	Current Home first choice?	Yes – 5 No – 3	Yes – 5 No – 1	
	Zarit Burden Inventory	39.25 (11.73)	16.83 (11.79)	**t=3.53, p=0.004**
	Satisfaction with care	3.88 (0.64)	4.5 (0.84)	t= 1.59, p=0.138
	SWC-EOLD	23.38 (4.78)	28.50 (3.89)	**t=2.21; p=0.047**

Staff	Age	38.9 (15.19)	52.7 (6.06)	**t=2.33; p=0.043**
	Gender	6F 2M	6F	
	Role	1 RGN; 4 Senior Care Attendants; 3 Care Attendants	2 RGN; 4 Care Attendants	
	Time worked in care home (years)	1.90 (1.11) Median 2	10.78 (10.69) Median 4.5	**Mann-Whitney U-test, p=0.001**
	WEMWBS	50.75 (8.19)	62.0 (4.52)	**t= 3.02; p=0.011**

for a mean of 15.6 months (*SD* 10.08) and for CH2 residents the mean duration was 21.5 months (*SD* 14.0); this difference was not significant. All the residents had a CDR score of 3 and a FAST score of 7. Three of the eight CH1 residents were mobile, compared with only 1 of the six CH2 residents. All of the residents scored ‘0’ or ‘1’ on the Katz ADL scale, indicating a high degree of dependence for care needs.

Resident quality of life scores

Care Home 1 relatives rated the quality of life (QUALID) of their residents slightly worse than those in Care Home 2 (19.38 *SD* 5.34 v 18.5 *SD* 2.26; *t*=0.416, *p*=0.686); both were slightly better than the mean family rating reported by Clare et al. (2014) (mean 21.66; standard deviation 6.71). Staff ratings were significantly correlated with relative ratings (Pearson’s *r*=0.46, *p*=0.048, 1-tailed), but staff reported a lower quality of life overall. In Care Home 1 the mean QUALID staff rating was 22.0 (*SD* 5.4) and in Care Home 2 the mean rating was 25.3 (*SD* 4.18), indicating lower levels of QoL given by staff in Care Home 2 than those of Care Home 1; Both indicated slightly worse QoL compared with the mean staff rating reported by Clare et al. (2014) of 21.96 (standard deviation 6.21). The difference between care homes was not significant (*t*= -1.253, *p*=0.234) but the overall difference between staff and relative ratings was significant (paired samples t-test, *t*=3.43, *p*=0.004).

Relative burden and satisfaction with care

Relatives of residents in Care Home 1 scored much higher on the Zarit Burden Inventory than relatives from Care Home 2 (39.25 (*SD* 11.73) v 16.83 (*SD* 11.79); *t*=3.53, *p*=0.004). The scores of Care Home 2 relatives are slightly lower than the average for family carers of people with dementia living in the community (mean 22.4, standard deviation 16.2; Hebert et al., 2000), whereas those for Care Home 1 relatives are much higher. However, relatives' satisfaction with care, rated from 1 to 5, did not differ between the two homes (3.88 (*SD* 0.64) v 4.5 (*SD* 0.84); *t*= -1.588, *p*=0.138).

Staff well-being

There was a significant difference in staff well-being, measured with the Warwick-Edinburgh Mental Well-Being Scale, between the two homes, with staff from Care Home 2 reporting higher levels of well-being, (CH1, *M* 50.75 (*SD* 8.19); CH2, *M* 62.0 (*SD* 4.52); *t*= -3.019, *p*=0.011). The Care Home 1 average staff score is consistent with the mean for the general population (mean 51, standard deviation 7) whereas the score for Care Home 2 staff is in the top 15% for the general population i.e. their reported levels of well-being are above average (Tennant et al., 2007). Overall, there were trends for staff who had worked longer in one or other of the care homes to be more likely to report higher well-being (Pearson's *r*=0.465, *p*=0.094). There was also a trend for staff well-being to be negatively related to relative's Zarit Burden Inventory scores (Pearson's *r*= -0.496, *p*=0.071), reflecting the differences noted between the two homes on these measures.

Table 6 3. Total scores on SWC-EOLD for the two care homes.

	Mean (SD)	Range	Median
Care Home 1 (n=8)	23.38 (4.78)	16-30	23.5
Care Home 2 (n=6)	28.50 (3.89)	25-35	27.5
Total sample (n=14)	25.57 (5.00)	16-35	26.5
	t=2.21; p=0.047		

Relatives' satisfaction with care at the end of life in dementia (SWC-EOLD)

Total scores for Care Home 1 were significantly lower than for Care Home 2 (Table 6.3). Relatives' SWC-EOLD Total scores showed significant correlations with the relatives' ratings of their overall satisfaction with care and showed a negative association with burden (Table 6.4). Relatives reporting more satisfaction with end of life care reported less care-related strain. Older relatives also reported greater satisfaction with end of life care. There was no association with the resident's quality of life as rated by the relative, nor with the frequency of visits or the length of time the resident had been in the care home. There was a trend (*p*=0.067) for staff ratings of *lower* quality of life to be associated with greater satisfaction with end of life care.

Table 6. 4. Pearson correlations between SWC-EOLD and other relevant variables.

	Relative's Age	Zarit Burden Inventory	Relative's Satisfaction with Care	QUALID rated by relative	QUALID rated by staff	Number of visits per week	Time in care home (months)
SWC-EOLD	**0.652***	**-0.591***	**0.596***	0.106	0.503	0.295	-0.155
Relative's Age	-	**-0.621***	0.488	0.065	0.208	-0.044	-0.140
Zarit Burden Inventory		-	-0.379	0.083	-0.286	-0.084	-0.027
Relative's Satisfaction with Care			-	0.310	0.261	0.123	0.235
QUALID rated by relative				-	0.463	0.335	-0.134
QUALID rated by staff					-	0.317	-0.078
Number of visits per week						-	-0.081
Time in care home (months)							-

Examination of ratings on the constituent items of the SWC-EOLD provides a more detailed view of the perspectives of the relatives from the two homes (See Table 6.5). There was a significant difference in responses between Care Home 1 and Care Home 2 relatives for five of the nine items on the SWC-EOLD scale, with Care Home 2 relatives responding more positively. For items 3, 4, 7 and 9, all the Care Home 2 relatives agreed or strongly agreed with the positively worded statement, whereas Care Home 1 relatives were much more divided in opinion, with a substantial proportion disagreeing in each case. These four items all related to the quality of care received.

Table 6. 5. Comparison of relatives' ratings on each item of SWC-EOLD for the two care homes.

		Care Home 1	Care Home 2	Kendall's Tau / significance
1) I felt fully involved in all decision making	Strongly agree	1 (13%)	3 (50%)	**T=2.39; p=0.017**
	Agree	2 (25%)	2 (33%)	
	Disagree	4 (50%)	1 (17%)	
	Strongly disagree	1 (13%)	0 (0%)	
2) I would probably have made different decisions if I had more information	Strongly agree	1 (13%)	1 (17%)	T=0.48; p=0.634
	Agree	2 (25%)	1 (17%)	
	Disagree	4 (50%)	2 (33%)	
	Strongly disagree	1 (13%)	2 (33%)	
3) All measures were taken to keep my care recipient comfortable	Strongly agree	1 (13%)	5 (83%)	**T=4.53; p<0.001**
	Agree	4 (50%)	1 (17%)	
	Disagree	3 (37%)	0 (0%)	
	Strongly disagree	0 (0%)	0 (0%)	
4) The health care team was sensitive to my needs and feelings	Strongly agree	1 (13%)	4 (67%)	**T=3.42; p=0.001**
	Agree	4 (50%)	2 (33%)	
	Disagree	3 (37%)	0 (0%)	
	Strongly disagree	0 (0%)	0 (0%)	
5) I did not really understand my care recipient's condition	Strongly agree	0 (0%)	1 (17%)	T=1.44; p=0.151
	Agree	0 (0%)	2 (33%)	
	Disagree	4 (50%)	1 (17%)	
	Strongly disagree	4 (50%)	2 (33%)	
6) I always knew which doctor or nurse was in charge of my recipient's care	Strongly agree	0 (0%)	1 (17%)	T=0.92; p=0.359
	Agree	2 (25%)	0 (0%)	
	Disagree	2 (25%)	0 (0%)	
	Strongly disagree	4 (50%)	5 (83%)	
7) I feel that my care recipient got all necessary nursing assistance	Strongly agree	0 (0%)	5 (83%)	**T=8.5; p<0.001**
	Agree	4 (50%)	1 (17%)	
	Disagree	4 (50%)	0 (0%)	
	Strongly disagree	0 (0%)	0 (0%)	
8) I felt that all medication issues were clearly explained to me	Strongly agree	0 (0%)	3 (50%)	T=0.55; p=0.584
	Agree	5 (63%)	0 (0%)	
	Disagree	3 (37%)	3 (50%)	
	Strongly disagree	0 (0%)	0 (0%)	
9) My care recipient received all treatments or interventions that he/ she could have benefited from	Strongly agree	0 (0%)	5 (83%)	**T=8.5; p<0.001**
	Agree	4 (50%)	1 (17%)	
	Disagree	4 (50%)	0 (0%)	
	Strongly disagree	0 (0%)	0 (0%)	

Negatively worded items shaded; significant differences between Care Home 1 and Care Home 2 relatives' responses indicated in bold.

On items relating to information for decision-making, explanation of medication issues and knowing which doctor or nurse was in charge of the person's care, there was little difference between homes, and a mix of positive and negative views in each home. However, Care Home 2 relatives did report being more involved in decision making overall. Half of the Care Home 2 relatives reported not really understanding the care-recipient's condition, whereas all the Care Home 1 relatives felt that they did.

Scores on several items (1, 3, 7 and 9) correlated significantly with both the 5-point Satisfaction with Care rating made by relatives and the Zarit Burden Inventory score (Table 6.6). Again, these are the items most directly associated with the quality of care. Relatives who visited more often were more likely to feel fully involved in decision making and that the healthcare team were sensitive to their own needs and feelings. Younger relatives were more likely to agree that more information could have made a difference to their decision making.

Discussion

In this chapter, the two care homes taking part in Study 2 have been described, and differences between them highlighted. Care Home 1 had recently come under the ownership and management of a small care home chain, and was undergoing a period of considerable transition, in terms of the built environment and the culture of care. Care Home 2 had a lengthy and stable history, had fewer residents overall and a smaller proportion of residents with advanced dementia. It enjoyed higher staffing levels, and its single communal lounge – whilst not in keeping with dementia design guidance (King's Fund, 2014) – meant observation and engagement were facilitated. There were no differences in demographic variables for participating relatives and their residents between the homes, but staff in Care Home 2 were on average older and had been working at the home for a much longer period of time.

In terms of the variables evaluated, the sample of residents in each home was remarkably similar. All the residents had a CDR score of 3 and a FAST score of 7 and all of the residents scored '0' or '1' on the Katz ADL scale, indicating a high degree of dependence for care needs. Level of dependency has been found to contribute to lower QoL ratings (Buckley et

Table 6. 6 Correlations between SWC-EOLD items and other relatives' variables

	Relative's Satisfaction with Care	Zarit Burden Inventory	Relative's Age	Frequency of visits
1) I felt fully involved in all decision making	.572*	-.549*	0.444	.554*
2) I would probably have made different decisions if I had more information	-.325	.473	-0.842**	-.076
3) All measures were taken to keep my care recipient comfortable	.840**	-.717**	0.448	.462
4) The health care team was sensitive to my needs and feelings	.212	-.509	0.025	.535*
5) I did not really understand my care recipient's condition	.009	-.369	-0.088	.160
6) I always knew which doctor or nurse was in charge of my recipient's care	.110	.130	0.277	-.178
7) I feel that my care recipient got all necessary nursing assistance	.717**	-.803**	0.490	.469
8) I felt that all medication issues were clearly explained to me	.182	-.064	0.151	.190
9) My care recipient received all treatments or interventions that he or she could have benefited from	.717**	-.803**	0.490	.469

Spearman rank correlations, two-tailed * $p<0.05$; ** $p<0.01$

al., 2012; Conde-Sala et al., 2009; Snow et al., 2005). In Care Home 1, three of eight residents were mobile, compared with only one of the six Care Home 2 residents.

A wealth of research showing the strain experienced by family caregivers of relatives with dementia exists (Chiao et al., 2015). There is also recognition that this a stressful role, and this stress does not end when the relative moves into care home placement (Gaugler et al., 2010). In this study, family caregiver strain was measured with the Zarit Burden Interview (ZBI), which indicated that relatives of residents in Care Home 1 reported significantly higher burden levels than relatives from Care Home 2. The Care Home 1 relatives scores were considerably higher than mean scores reported for family caregivers providing care for a person with dementia at home. More participating relatives in both homes were female, consistent with other studies (Abreu et al., 2018; Caron et al., 2005; Hong & Kim, 2008) and the most common relationship with the PLWD was adult child, with participating relatives of Care Home 2 slightly, but not significantly older, than of Care Home 1. Across the two homes, strain was greater in younger relatives, and higher in those less satisfied overall with end-of-life care on the SWC-EOLD, reflected also in higher strain being related to less satisfaction on a number of the individual items relating to the care received.

Although the difference was not significant, relatives of residents in Care Home 1 visited less frequently than those in Care Home 2. Previous research (Grabowski & Mitchell, 2009) found higher frequency of visits associated with less strain, suggesting that visiting alleviates some strain and possibly relatives benefit from support offered by the home. However, no association in this sample was found between frequency of visits and strain reported by relatives. Frequency of visiting did correlate with two items on the SWC-EOLD, suggesting that relatives who visited more often felt more involved in decision-making, and that staff were more sensitive to their needs. It therefore appears that relative strain is strongly associated with satisfaction with end-of-life care, but, in this sample, frequency of visiting is not the only factor involved.

There was a significant difference in staff well-being, shown on the WEMWBS (Warwick-Edinburgh Mental Well-Being Scale) between the two homes, with staff from Care Home 2 reporting higher levels of well-being. Care Home 1 staff reported well-being levels consistent with those of the general population, whereas Care Home 2 had much higher well-being than average. Again, it is important to consider between both homes, the mean age of the participating staff, as in CH2 the mean age was significantly older. In addition, in terms of employment duration, staff in CH2 had a significantly longer duration of employment. According to the demographics collected for both care homes, the level of staff turnover is significantly higher in Care Home 1. Increased levels of work-related stress have also been linked with high levels of staff turnover (Brodaty et al., 2003; Costello et al., 2019; Larabee et al., 2010), absence, reduced performance, and a negative impact on care provision (Bostick et al., 2006; Castle & Engberg, 2005). Furthermore, where levels of staff turnover are higher, this may reduce the sense of community within the home, and the staff peer support system, possibly increasing the need for agency staff.

Across both homes, clear differences exist in terms of the layout. In Care Home 2 residents sharing the one space may have reduced the staff workload. Furthermore, the living space may have promoted a sense of community and encouraged staff peer support, especially as the living space also includes the manager’s office. Greater manager support and peer support has been identified to increase well-being and job satisfaction (Albers et al., 2014; Costello et al., 2019; Gerikiene, 2007; Jeffrey et al., 2019). However, for staff in Care Home 1, navigating several areas could have possibly increased the demands, and contributed to a reduced sense of community. In line with our findings for Care Home 1, Costello and colleagues (2019) identified higher burnout level and stress with: lower job satisfaction, lower perceived adequacy of staffing levels, poor care home environment, feeling unsupported and rating home leadership as poor. Further, concurrent studies have found higher burden, where staff struggled to balance care expectations, organisational constraints, their desire to provide compassionate care, and their ability to meet this demand (Christiansen et al., 2015; Cooper et al., 2018; Kadri et al., 2018). Not only do these procedures affect the personhood of residents and challenge staff self-worth and identity (Higgs & Gilleard, 2016), they diminish staff ability to view their occupation as dignified and worthwhile.

In contrast with previous studies of people living with mild to moderate dementia, here relative’s strain was not associated with lower ratings of QoL of the resident. This finding could suggest that whilst relatives’ own well-being is affected by the quality of care their resident receives, it is possibly harder for them to make judgements regarding the resident’s QoL beyond the context of the severe dementia and the accompanying changes to the person and their relationship with the person. It appears that, from the relatives’ perspective at least, quality of care does not necessarily indicate perceived quality of life. Perhaps from the relatives’ perspective, rating QoL on a scale such as QUALID proves difficult, as the QUALID asks for the responder to provide ratings for observations made during the preceding seven days, hence challenging for those who visit weekly or less frequent. Family members were more likely to be adult children than spouses, who visited the resident mostly once or twice weekly, and not for extended periods of time.

There were no significant associations between staff-rated QoL and satisfaction with care as rated by relatives, or relatives' strain. Across both homes, staff rated resident QoL significantly lower than the relatives did. In contrast, whilst staff in the study reported by Clare et al (2014) did report lower quality of life on the QUALID than relatives, the difference was not significant. The correlation between relative and staff ratings on the QUALID was similar in both studies (*r*=0.46 in current study; Clare et al *r*=0.41). It is noteworthy that the higher well-being reported by Care Home 2 staff does not lead to ratings by staff of better QoL on the QUALID, with the mean rating in fact being (non-significantly) worse, and higher than in other Homes from the same region (Clare et al., 2014). This is in contrast to a suggestion from the Clare et al (2014) study that staff well-being was related to ratings of better QoL for residents, although this study also found that staff reporting greater emotional exhaustion also rated QoL as better, so the pattern of associations is unclear. Previous research findings suggest the differences between staff and family ratings of QoL could also be explained due to the time staff spend with the residents, and the differences in the nature of the interactions they have, and increased knowledge of their behaviours, distress and daily lived experiences (Clare et al., 2014; Griffiths et al., 2020; Robertson et al., 2017).

The trend for staff to rate higher QoL, where relatives' satisfaction for end of life care was less, is difficult to explain, and may be a chance association. Further examination of how staff members view aspects of residents QoL is required. It may be for example that Care Home 2 staff having worked longer in the Home may have seen more deterioration in their residents and are influenced by this in their judgements. This may have led to the staff in Care Home 2 to compare the past with present, having witnessed the decline in the residents. Studies have found proxy ratings decline over time, with progression of the illness (Bosboom et al., 2013). Further, previous research found lower staff ratings of QoL, where more permanent staff to resident assignment existed (Zimmerman et al., 2005) and a higher number of days worked preceding the rating (Graske et al., 2014).

Despite differences between the care homes, the lack of differences on several items on the SWC-EOLD suggests some common areas of challenge in providing support for people with advanced dementia towards the end of life. Whilst relatives from Care Home 2 expressed general satisfaction with the quality of care provided, families in both care homes expressed dissatisfaction with aspects relating to information regarding their relatives' medical care. Specifically, relatives felt they did not receive enough information regarding medication, or as to which doctor or nurse was in charge of their resident's care. A number of relatives reported that they did not really understand their resident's condition and that with more information they might have made different decisions. These results indicate the importance of family involvement and communication in advanced dementia care. Increased communication with families, discussing care planning may further support their satisfaction with care, and the results suggest that involvement in decision-making is associated with reduced strain in relatives. All the Care Home 1 relatives reported having a reasonable understanding of their relatives' condition, whereas half the relatives of Care Home 2 did not. The combination of understanding and yet lack of involvement in decision-making seen in Care Home 1 could have decreased their satisfaction with care, with their lack of involvement contributing to their feelings of strain. Family caregiver strain has been reported to be linked with lack of decision-making and involvement, in previous research (Engel et al., 2006). Results from this study indicate communication with the family is an important aspect of satisfaction with care, and possibly greater attention to family preferences and views may support relative well-being, particularly supporting families with initial care home placement and their transition in their role.

With regards to visiting, satisfaction with care, and staff being mindful of families' feelings, it has been suggested where relatives are dissatisfied, this may lead to avoidance behaviour by staff, consequently increasing dissatisfaction (Grabowski & Mitchell, 2009). The results in the current study are in contrast to previous studies, where greater dissatisfaction has been associated with higher frequency of visits, and anxiety (Grabowski & Mitchell, 2009). In the current study, frequency of visiting did not relate to overall satisfaction with care or relatives' strain. However, it was related to relative reports of greater involvement in decision making and feeling that staff were sensitive to the relatives' needs – both areas where Care Home 2 was rated significantly higher than Care Home 1. Care Home 2 relatives were also more satisfied with the care and reported less strain and visiting possibly increased their opportunity to liaise with the care home staff about the care provided and their involvement. In this study, greater visiting frequency appeared to enhance involvement in decision-making and positive relationships with staff.

The role of decision maker in this context is often not well defined. Frequency of visiting had been found in a previous study as correlating with decision-making, where families also expressed the need for formal meetings regarding medical needs (Grabowski & Mitchell, 2009). Given a range of responses with regards to information and decision making in this study, it may be that the care home staff aim to relieve some of the strain of family members, as opposed to not keeping them informed.

For some family members in these situations, there is a complete element of trust in the professional caregivers to make the most informed decisions, as they perceive them as professionals with the medical knowledge, and are therefore satisfied with their approach, as they do not feel that they are competent in this area. However, other relatives see themselves as having knowledge of what the individual would want, and a level of trust will need to be built over time, through interactions with the care staff team (Miller et al., 2014). Relatives identify themselves as the person who the PLWD would want to make decisions regarding their care and knowing what the individual would want (Feinberg & Whitlatch, 2002).

In the next chapter, issues around decision-making, family involvement and relationships, and their impact on residents' well-being are explored in greater depth through interviews with staff and relatives in both homes.

Strengths and Limitations

The use of standardised questionnaires adds to a detailed description of the care homes and of the three stakeholder groups: residents, relatives and staff, and provides information about some clear differences between the homes, as well as some similarities. However, the exploratory nature of this research study means that any conclusions regarding the interaction of the various factors studied must be tentative. In particular, the small sample size limits the statistical power and the striking differences between the two homes may have led to spurious correlations, for example between staff well-being and relative strain. The small numbers meant that correlations for example between staff well-being and length of time worked in the home could not be evaluated in each home separately.

In Care Home 1, several relatives that could have taken part in this project declined or did not respond to the invitation to participate, limiting the range of relatives taking part. Several relatives, who were involved to some extent at the home, did not wish to participate because they were unhappy with the home coming under the management of the organisation, either because of previous dealings with the organisation or because of their perception of it. The relatives discussed with the researcher, how this discouraged them from participating in the project, as they felt the project could endorse the company, and were unable to view the project separately from the organisation. This may have led to participation bias within our participating relatives, where people who took part in the study were more satisfied with the care home overall. Furthermore, I was unable to recruit several family members who were not local to the area, and therefore, could not account for their experiences as relatives, or the effect on residents of having a more distant relative.

Chapter 7: Advanced dementia in care homes: a mixed-methods, multiple perspective, collective case study evaluation – II: qualitative findings

Introduction

In the previous chapter, the context for this mixed-methods study was set out, in relation to the challenges facing care homes and their staff as they seek to provide care and support, including end-of-life care, for people with advanced dementia. The importance of the relationship between care homes and family members of residents with advanced dementia emerges from the literature and from Study 1 (Chapters 4 and 5 of this thesis), reflecting the triangle of care (RCN, 2014; Woods et al., 2008 p.14), with family members taking on a variety of roles from advocacy and monitoring to hands-on personal care.

In Chapter 6, the two care homes constituting the collective cases for this study were described, purposively different from each other and from the care homes included in Study 1 in many respects. One was a home in transition, the other a stable, settled environment. They differed in number and mix of residents and in staff-resident ratios. In one home, staff turnover was higher, and staff were, on average younger. The scope of the study was also further extended from Study 1 in that in both homes the participating relatives typically did not visit daily.

The quantitative data reported in Chapter 6 showed that staff from Care Home 2 reported better well-being than those from Care Home 1, and that relatives showed a similar pattern, with less strain reported by those from Care Home 2. Care Home 2 relatives reported greater satisfaction with end of life care, overall. However, this difference was not apparent on all the items of the scale used, with relatives from both homes expressing dissatisfaction with certain aspects of care, especially around information regarding medical matters. Despite the evident differences in well-being and strain between staff and relatives of the two homes, there was no difference in quality of life reported for the residents, whether rated by staff or relatives. The levels of overall impairment and dependency levels of the residents were similar in the two homes.

In this chapter, I report on the qualitative interview data from the two care homes, supporting two of the study aims specifically:

1) To consider in more detail well-being of staff and relatives and satisfaction with care.

2) To explore human rights considerations in more detail than proved possible in Study 1, by an even greater focus on this in the fieldwork undertaken.

In addition, given the lack of a difference between the care homes in reported quality of life of the residents, despite the evident difference in satisfaction with end-of-life care, factors influencing resident well-being and quality of life are explored in more detail.

Methods

Design

As stated in Chapter 6, and also discussed in Chapter 3, this study uses a collective instrumental case-study design (Stake, 2005; Baxter & Jack, 2008). Collective case-study, according to Stake (2005, p.445) is an instrumental type of case-study, involving 2 or more cases. 'Instrumental' case-studies differ from 'Intrinsic' studies in that the interest is not simply on the particulars of the individual case, but on an understanding of broader issues. The issues for this research study are:

- Well-being and QoL of residents with advanced dementia in care homes, and the well-being of their relatives and staff caring for them
- Human rights of residents in care homes with advanced dementia

Two individual care homes, selected to provide a wide range of experiences and contexts, served as cases, to enhance our understanding of these issues. For the qualitative analyses reported in the current chapter, each home was examined first as an individual intrinsic case, with embedded constituencies of relatives and staff. Subsequently, a cross-case analysis was conducted, examining themes, similarities, and differences across both cases. This method of analysis allows for further exploration of factors that may have contributed to the outcomes of the case, and explanation as to why factors may exist in one case and not in the other. However, the focus is not on the comparison, per se, as Stake (2005, p.457) argues that this distracts from a full understanding of the complexities involved. Rather, employing a cross-case analysis, allows the exploration of factors in different settings and communities, and opportunities to learn from separate cases, whilst preserving the essence of the initial case and adding to our overall understanding; '…illustration of how a phenomenon occurs in the circumstances of several exemplars can provide valued and trustworthy knowledge' (Stake, 2005, p.458).

Settings and Participants

The settings are described fully in Chapter 6. Descriptive details of the residents and participating relatives and staff members who contributed are also provided in Chapter 6 (Table 6.1). In brief, a total of 14 relatives and 14 staff were interviewed: eight relatives and eight staff members (in each case six female, two male) participated from CH1 and six relatives (four female, two male) and six staff (all female) from CH2. Staff from CH2 were significantly older and had been employed for a longer duration at the home. All the relatives' residents met the study criteria for advanced dementia and needed extensive help with basic activities of daily living.

Semi structured interviews

An interview topic guide was developed, drawing on topics discussed and outcomes from the previous study (see Chapters 4 and 5). The researcher conducting the interviews was a familiar face within the homes and the researcher continued to see participants at the home after their scheduled interviews, whilst they visited residents. Therefore, the researcher had the opportunity to build a rapport with participants before, during and after interviews. Interviews conducted lasted between 15 and 60 minutes, and the interviewer advised participants that they could ask any questions during the interview and that there were no correct or incorrect answers. Participants were encouraged to talk freely about the topic area and the researcher ensured sensitivity toward self-expression and participants giving their own accounts about their personal experiences. If participants were unsure, the interviewer would explain further, and participants were encouraged to talk about the subject area as they wished. To assist participants respond to the human rights questions, the researcher provided participants with a copy of the DEEP 'Our Dementia, Our Rights' guide (DEEP, 2016), written for and with individuals living with dementia, setting out simply the key domains: equality, inclusion, privacy and security, dignity and the right to life.

Data analysis

Interviews were transcribed from digital recordings and all personal identifiers removed; participants were assigned a pseudonym and participant number. The researcher listened back to the recordings to ensure accuracy of transcription and coding. The qualitative research software programme NVivo was used to support coding and analysis of the data to enhance rigour. As discussed in Chapter 3, an inductive thematic analysis approach (bottom up) was adopted (Braun & Clarke, 2006), and a framework was developed for identifying and coding words and phrases of importance. The researcher identified some themes that were linked to the topic guide during the coding phase of the analysis. Therefore, an inductive and deductive approach took place during the course of the initial data analysis (Huberman & Miles 1994).

Initially, the researcher analysed the data for each case individually, following Stakes' (2005) methodology for case studies. Potential themes were identified (see Appendix DD for an example transcript section) before further analysis using the NVivo software to support coding of the data and identifying themes. During this procedure, the researcher placed extracts of the interview transcripts into nodes identifying initial themes. Initial themes were reviewed to ensure the extracts fitted the given theme, and no further relevant extracts were within the data set.

The researcher focused on analysing cases individually, returning to original transcripts and repeated the coding process, ensuring that nothing was missed, so that as much understanding as possible of the intrinsic cases was obtained (Stake, 2005, p.450). At this stage, relatives' and staff interviews were analysed separately. The researcher coded the data independently and met regularly with the research team to discuss the coding process and identified themes (Stake, 2005 p.453). The themes and subthemes were refined and modified with the research team (see Appendix EE for a graphic representation of this process) to ensure validity and a final consensus was reached.

A cross-case analysis was then undertaken with the research team, involving re-reading of transcripts, comparison of themes generated for the individual cases, triangulating relative and staff themes and further reflection. This process (see Figure 7.1) led to a set of themes applying across the cases that reflected aspects of relationships and the relationship-context within the homes, as well as perspectives on human rights.

Results

Initial within-case thematic analysis

The qualitative data was first analysed for each case (care home) separately, with relatives' and staff interviews within each home generating distinct themes. These themes and sub-themes are summarised in Tables 7.1 to 7.4, providing a brief description of each theme. To avoid repetition, a full account of these themes is not provided here, as the cross-case analysis, drawing on many of the same interview quotations, addresses more directly the study aims.

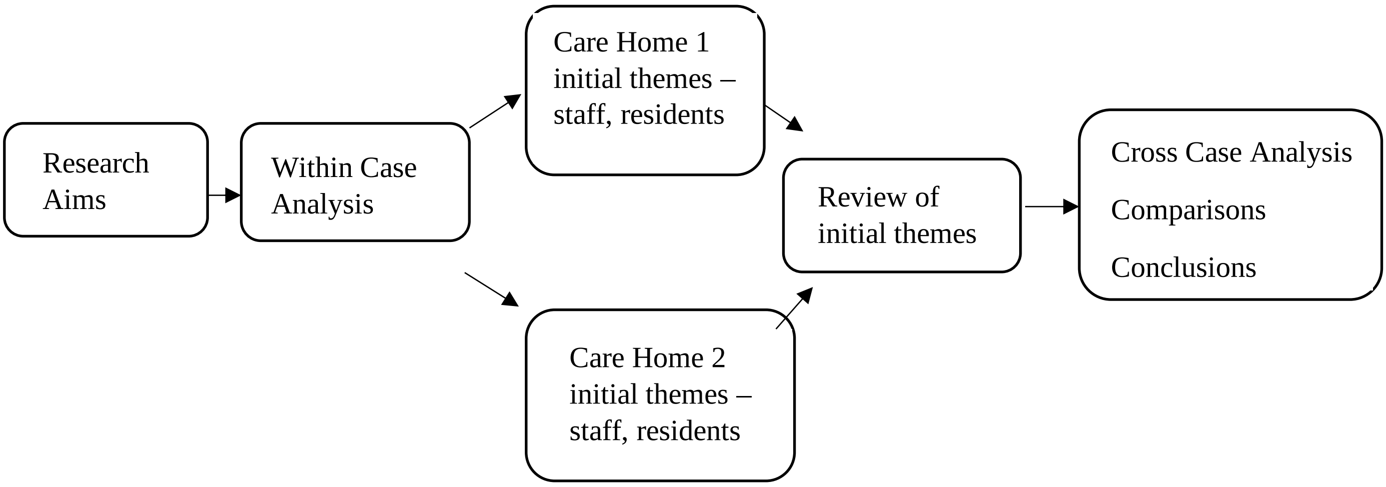


Figure 7. 1 Cross case-analysis process

Table 7.1 Care Home 1: Relatives' themes and subthemes.

Themes and Subthemes	Description
Physical care *Staff Workload*	Relatives discussed the physical needs of residents being met by staff supporting the residents' well-being. However, in terms of enhancing QoL, they discussed the importance of meeting needs beyond those relating to basic care but were appreciative of the constraints and pressures experienced by the staff.
Activity	Whilst relatives were satisfied where residents had undertaken activities at the home, they expressed concern for the majority of their days, which were spent unoccupied, reducing their QoL.
Family providing Interaction *Non-verbal methods*	Families provided interaction and activity for the residents. They discussed using devices and strategies to support their interactions. Relatives discussed the non-verbal means and methods of communication with the residents, and the importance of non-verbal communications.
Family involvement/lack of *Relative-staff communication*	The relatives spoke of positive interactions between themselves and the care home. However, they explained there is not enough communication between them, and the need to establish a relationship, between themselves and the care home, which in turn would benefit the residents.
Human rights *Choice and Opportunity*	For most part relatives felt human rights were being maintained through standard of care. A number of relatives did speak about instances where human rights were being compromised. Despite this, relatives felt the residents were given choice and the right to refusal, although their personal preference may not be within their best interests.

Table 7.2 Care Home 1: Staff themes and subthemes.

Themes	Description
Role & Culture *Time and activity* *Staff attitudes*	The staff discussed having role satisfaction and link with their own personal experiences of caring for their loved ones. They referred to the lack of time they are allocated to spend with the residents, and the differences in their views and approaches, regarding care delivery.
Physical signs *'We know them'*	The care staff explained how they work closely with the residents throughout the day and pick up on physical signs and behaviours relating to well-being. They also spoke about having an increased understanding of residents' behaviours, daily routines and preferences.
Communication *Choices*	Staff referred to their communication methods with the residents and how this may need to be modified; they discussed rephrasing, allowing time to respond and reassurance. They explained how they enable residents to make their own choices as much as possible, ensuring the residents understand, modifying their communication and allowing plenty of time to respond.
Human Rights *Best interests*	For most part, the staff discussed how the residents' rights are being retained, through care and safety the home provides. However, they spoke about their rights being conflicted, under the time restrictions that they work under, and complex situations, where residents require support that they do not wish to receive.

Table 7.3 Care Home 2: Relatives' themes and subthemes

Themes and subthemes	Descriptions
Monitoring and responding *Standard of care* *It's my social life*	Relatives placed emphasis on the staff's continued monitoring and response to individual and evolving needs. The relatives referred to the residents' well-being being promoted through the high standard of care. Further, families referred to their own well-being, feeling included in the home life and being encouraged to partake in their daily activities.
Relative providing interaction *His/her own way*	Within this theme, relatives focused on their interactions with the residents and how they keep the conversation ongoing, regardless of limited verbal ability. Families talked about their residents having their own unique ways of communicating and discussed the importance of non-verbal communication.
Human rights *I belong here* *Care*	The relatives discussed the residents' rights being promoted, receiving specialised care that maintained their personhood. The relatives also discussed the importance of their family life and involvement, being welcomed by the home.

Table 7.4 Care Home 2: Staff themes and subthemes

Themes and Subthemes	Descriptions
Because we know him *Monitoring and responding*	The staff discussed contributors to and indicators of well-being were derived from ‘knowing’ the resident as an individual. They spoke about the residents’ needs being continuously monitored by the staff and updating care plans, as needs evolve.
Opportunity	The theme relates to the communication between staff and residents, and their focus on providing the residents with opportunities. The staff emphasised the importance of promoting the residents’ independence wherever possible. They discussed promoting their opportunities to partake in social interaction, and contribute to daily decisions
Continuity and knowledge *Best interests*	The rights of the residents were promoted through the continuity of the care that they receive at the home, the staff discussed the benefits of having a low staff turnover. The staff discussed the residents’ right to refusal, and situations where they would have to make decisions on their behalf would only be within the resident’s best interests.
Team effort	The theme was largely centred on the benefits of being a part of a supportive team for both the staff and the residents. The staff discussed the openness in communication between them and the management team and feeling valued as employees.

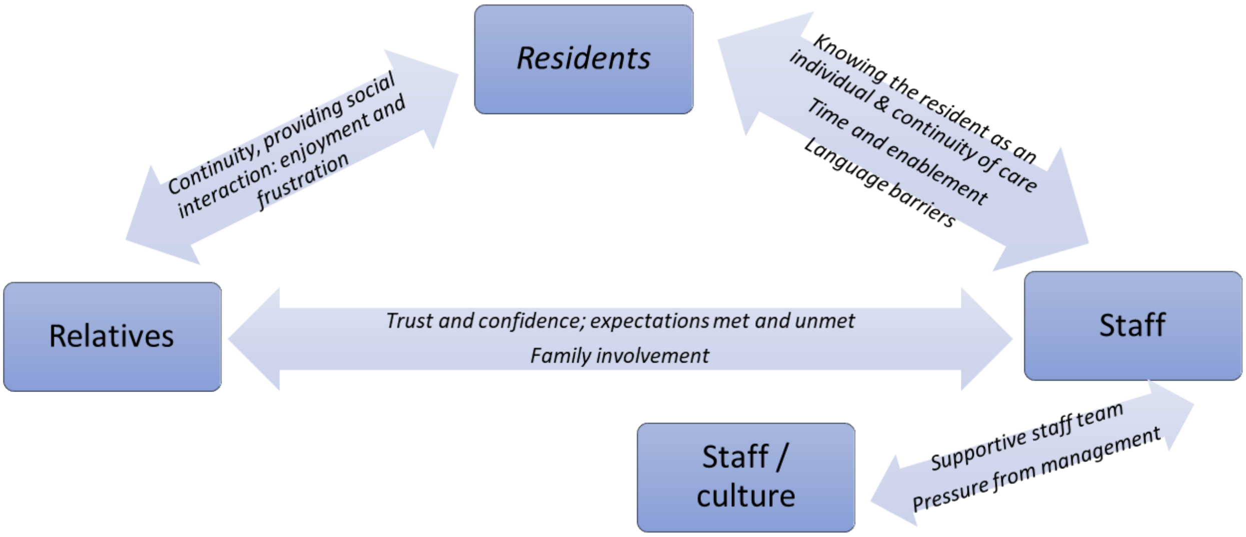
Cross-case analysis - Relationships, Well-being and Human Rights

The cross-case analysis identified two major themes that underpinned the themes and sub-themes, for both relatives and staff across both cases. The first of these was Relationships and Well-being, evident in themes reflecting interaction and communication between families and residents; family involvement; communication between staff and residents; communication between staff, in working as a team and the constraints of the organisation; staff knowledge of residents; relatives’ awareness of and concerns regarding physical care and activity (reflecting the relationship between relatives and the home). Analysis indicated that the strength of these relationships, and the tensions within them potentially had implications for all parties and directly influenced one of the issues addressed by this research: QoL and well-being. Thus, the impact of relationships was evident on the well-being of all involved: residents, relatives and staff.

The second major theme was Human Rights, evident as a distinct theme for relatives from both Homes and for staff from Care Home 1, and also in the ‘Continuity and Knowledge’ theme for staff from Care Home 2. The two major themes were not entirely distinct, as aspects of relationships did have important consequences for the promotion and protection of human rights in the Homes, especially in relation to family involvement supporting the maintenance of the right to a family life.

In the sections that follow, supported by quotes from interviews with relatives and staff from both Homes, there is first a presentation of what emerged from the interviews regarding four key sets of relationships: i.e. between relatives and staff; between relatives and residents; between staff and residents; and those between staff and between groups of staff in the two homes, with these relationships and sub-themes shown in Figure 7.2. The implications of these relationships for the well-being of residents, relatives and staff respectively are then drawn out. The evidence emerging from the interviews regarding Human Rights is then presented, organised in relation to recognised Human Rights relevant to this context. Any names in the quotes below are pseudonyms to ensure the anonymity of participants.

Figure 7.2 The key relationships (with sub-themes) emerging from the cross-case analysis



The relationship between relatives and staff

Trust and confidence; expectations met and unmet

In CH2, relatives appear to trust staff, describing them monitoring residents' needs, taking action as required, and responding positively to any concerns raised. Relatives spoke about their resident's care and medical needs being continuously monitored at the care home and having information fed back to them. Families found it comforting to know that the staff kept them informed and were responsive to their needs.

"The staff here were brilliant, the hospital discharged too early, and of course she was coming back here, (to the care home) and within a day going back (to hospital), because her oxygen levels weren't high enough. They're pretty good at that stuff, they knew straight away, and were on the phone to say mum's going back in, or we're getting the doctor out" (Relative CH2)

'They are really good, when I've spoken with them about mum, they had already contacted the GP about it anyway; they just know these things' (Relative CH2)

Relatives felt confident in their involvement within their resident's care and when a situation does arise, the staff communicate and make contact with them. Conversely, relatives felt that they could approach the home regarding their resident's care, about any concerns, and they would respond effectively.

"They are really good. They ask, because she has meds in the afternoon, diazepam, they phoned me about the tablets, you know 'what do you want us to say?' They didn't just want to give her tablets without asking me first, because they know she wouldn't want to take them, if they say it's to help with whatever, she's happy with that. They did ask me, what did I want to say? You know, they could just say it's to calm her down. They're good with working round her needs, not cancelling her needs and her as a person". (Relative CH2)

In contrast, in CH1, relatives see staff as over-worked, and so not able to meet needs in relation to activity or mobility, for example.

"It's his mobility that's worrying me more than anything; that he's not getting up to walk. I think the nurses know that, but I don't think they are able to make that happen, because there isn't enough staff and there's bells ringing. He is lonely and they've said to me they haven't got the time to sit and talk. His physical needs are well cared for, with the staff, I think for his sake and for them, they need to have more of them. I think when somebody's living long term, it's part of their quality of life. Someone should be able to go and talk to them or take them out for a walk. His mobility is very reduced, but it is important for him that he is able to walk, even to the toilet and back. But I've seen them sometimes; they haven't got the time to do that and that's really sad" (Relative CH1)

Staff in CH1 report failing to meet their own expectations as well as those of relatives, again pointing to the lack of time:

"I struggle, I think people know that. It's just I try and give the best that I can, and sometimes and I know that things are changing, but it just isn't enough for the relatives. And they get angry because they think we can't be bothered, but it's just the time" (Staff CH1)

This shared awareness between both staff and family members that expectations of care needs are not always being met, causes distress to both parties, leading to tensions in the relationship between staff and relatives.

Despite expectations not always being met, for the most part, relatives explain how their residents receive good basic care at the home. They refer to attentiveness of the care staff to the residents' evolving needs and being prepared to refer residents to outside services when they are required.

"They look after his feet and they do everything like that, and you know that's important to me. The other things I can just, well they're things that I think are important you know so… The care, medical care that's there, that's good. There could be more of the other one I think, activities that's what's needed". (Relative CH1)

There were some indications that some staff were more responsive than others:

"The nurses are quick to pick up on anything that's wrong, they are very good, and they will refer him to the doctor, and they sort it straight away. I know they'll do it, and I know that the staff, just don't have the time and some people are more careful aren't they? ….other people aren't doing that as much, which is understandable, because they're rushing off to do something else or they aren't trained that way, It's difficult isn't it. Their medical care is amazing, there's nothing out of place. The personal care is incredibly good, they do look after them. Every time I visit he's clean and looking lovely. Things like that for me are important, and I think they are doing an excellent job looking after those needs" (Relative CH1)

However, a number of relatives discussed their concerns in terms of the continuity of care for residents following referrals to outside services and the continuity of care as an outcome, and report monitoring their resident's needs themselves:

"She's got cellulitis, then there's swelling and weeping. She had cream from the doctor. I assumed that the carers were putting the cream on for her. I was here one afternoon, and they'd all cracked. This was three days after it was prescribed, the cream was still sealed. I

thought, you're supposed to be applying this cream for her, you know it takes up no time does it? When I'm here – I do it". (Relative CH1)

Family involvement

For their part, CH2 staff value family involvement in supporting the resident and in care-planning. Staff explained how they discuss care planning with family members and feel that family involvement is of benefit to the resident, with the resident having someone else in their corner 'looking out for them'; an additional person monitoring their well-being. They discussed the benefits of having contact with relatives regarding the residents as they can use them to an advantage to gain information about the individual prior to care home placement.

"Bob can't make those decisions within his own best interest, so we make sure that decisions are within his best interest. His daughter visits, which helps, because we can discuss and she can discuss with us as well, what she thinks" (Staff CH2)

Staff consider the families a benefit to the resident's well-being and appreciate how much families are able to provide the residents outside of what they receive from the home environment.

"She's got a good support network, her family, it makes her happy; she is very orientated towards her family. They can come whenever they like, they can chat whenever they like, and incidentally Andrea has the opportunity to go home and she likes that." (Staff CH2)

Staff participants spoke about the care home as a 'home' for both resident and their families, referring to everyone as 'one big family'. The staff consider taking care of families, as well as the residents, a fundamental part of their caring role

"Norman does make a lot, but if he's not about he's very, he trusts us and we constantly keep her routine. She's awake in the day, we do everything we know that he would want for her because he is very protective and personally, I think that is very, very important to meet the family needs. To meet what the families ask of us, it's very important". (Staff CH2)

Family members discussed feeling welcomed into the home and a having a sense of belonging within the home, taking part in activities and benefiting from social events. Further, families explained how transition into care home placement can be difficult, and how the staff in the home had supported them throughout the journey, contributing to their own well-being:

"It's just, you know, little things. It's not a job, I don't think they do it as a job. It's what they want to do. You're a carer, you either have it or you don't. I had become clinically depressed. I didn't know it, I didn't know, that's what was wrong with me. I was crying anytime anyone spoke to me and not sleeping. It's only because of being here, having these guys here to pull me through. I went to see a GP and joined other groups, I tell everyone, they really have saved me" (Relative CH2)

Although a lack of communication was felt by families with the staff at CH1, care staff there referred to family involvement, and having built good relationships with a number of families, referring to their ease about consulting with them about care planning:

"If it's anything care wise, I talk to staff or whatever, and see other people's opinions. And then, like, about her personal belongings and all that, I talk to her family. I get on well with her family, so I always think that's important as well, you know" (Staff CH1)

However, it was clear this was not the case with every family and a number of staff members reported feeling that they are continuously under scrutiny by the relatives' monitoring of the residents' care.

"Her son is very critical, anything yeah. So, it's lovely that he comes to see his mum, but at the same time it is as if he's trying to make our job harder, picking on little things" (Staff CH1)

CH1 relatives considered it important that the care home establish a relationship with them, as well as with the residents. Some relatives were eager to build relationships with the care staff, and to provide their support, where they can, and continue their involvement in their resident's care:

"I've a list of points that I want to chat with about and that is one of them, to actually have, in a way a report on mum; good, bad, what problems is she causing there, and can we do something to help? To have some information coming back would be a benefit, and I think that promotes involvement both ways. I think that is something they possibly need to address. It's important for us to build that relationship, it's important to us" (Relative CH1)

One relative was especially pleased when she had a discussion with staff about her mother-in-law, and found herself able to continue to provide some form of care:

"I came in one time and she hadn't been here long, and her nails were getting a bit long. The carers said, 'we'll do that' you know, things like that, but I said 'no',' I'll do it'. I feel like I'm able to do it, you know. Like it was toilet time once, when I was here and I said, I'll take her, and they were happy for me to take her. Just little things like that, you know". (Relative CH1)

A number of CH1 relatives reported a lack of communication between them and the staff regarding their relative's daily routines and care planning, often leading to confusion why something had been changed, or why something had not been completed. Family members described changes in their resident's care without their knowledge or input causing distress, as they felt that they no longer had a voice and they must go with 'what the home says'. Relatives may not feel involved in decision making and care planning and report a lack of information.

"I don't get informed. Changes - mam's gone from having solids to a liquidized diet and I wasn't told. I just had to find out for myself, so you know it's… and the same with the drinks; I don't feel as if I matter. It is very distressing sometimes and there's sometimes you think, well you just take things in your stride and others..." (Relative CH1)

"Well, we don't really… (family involvement). It's whatever the home says we really (shrugs shoulders) you know it's them that tell us. How do I make decisions? Obviously if I've been advised, or if they've spoken to me, which isn't very often. There has been GP's before and there's a care plan in place and there's end of life, that's been put in place, so we have had involvement, but I don't feel involved in the day to day. Nobody says, 'is there anything you would like to have a chat about'. There is a box over there for suggestions but that's not the same is it. . I just don't feel involved, but I'm here and I can make some decisions for mam" (Relative CH1)

The relationship between relatives and residents

Continuity, providing social interaction, enjoyment and frustration

In CH2, relatives discussed a sense of being at home with their residents and the continuation of their relationship. Relatives provided social interaction for their resident, often describing enjoyment (but also frustration at times).

Relatives spoke about how care home placement had impacted on their lives, with relatives naturally feeling a sense of loss. However, one participant explained how her mother's transition into care home placement had benefitted her relationship with her, and effectively given back their mother-daughter relationship and family life.

"I can go away for the weekend and know that she's safe, whereas before, it scared the life out of me. It puts a strain on my relationship with my husband, children and everything. Then you get that feeling, not resenting them but.. I can't go away. At home, I was going round to visit.. I wasn't really, I was going to do the cleaning and make sure she had everything she needed. There was no time to actually sit and talk to her. Now, I come here, I just sit and talk; she can be my mum again now. We can actually sit down, and have a conversation, not that she does back, but it's lovely, just to be with her..to just think, I'm going to go and sit and talk with mum for a bit" (Relative CH2)

Participants discussed many ways they enjoyed spending time with their relatives and the interactions they had, often being taken by surprise by the clarity of some sentences and phrases:

"I'm always watching because she sometimes goes for my glasses, she (gestures: pats husbands head) 'where's your hat'? Where does that come from? How does she do… (laughs) then you can ask her anything and she can't, or she can't ask for what she wants. But these sentences come out., Just out the blue. The eyes are worth watching, her eyes say so much, I've always found. If I'm asking her something, she says yes, other times there'll be nothing, or a little nod and it's so subtle" (Relative CH2)

Families felt they were enabled by the home to have the confidence to continue with their family life with the resident, despite care home placement, and continue with routines and engagements they had prior to placement:

"She's well looked after, the staff do so much for all of them, I always joke I'm booking my bed (laughs). She always eats you know, always, so if she isn't that's when we know something isn't quite right. What I do is, because I live down the road, whatever meal I'm cooking in the night before I come in, I put some aside and take it in for her lunch, then she's not missing out is she? (Relative CH2)

Relatives discuss taking the resident out and continuing with their lives as part of the community. One relative explained how they continue their lives as a couple, despite his wife now living in the home:

"We've only recently got a proper wheelchair for her and I've been promising her to take her places we used to go and I go, only within walking distance. I go to church on a Sunday and Monday evening church, and they have a coffee morning on a Tuesday. I've taken Martha down there, and all these old ladies queuing up to speak to Martha (smiles). Some will say to me, you're doing a wonderful job, and I'm like (cross face) it's not a job, it's not, it's what you want to do" (Relative CH2)

However, one husband discussed how he has become frustrated with his wife at times, when she had been unresponsive:

"She just doesn't talk to me, and some days I have to be quite sharp with her, and say look, I'm talking to you (shakes knee, gesture) now give me an answer! Then [CH manager] will look at me. I'm not aggressive, I'm not that sort of person, but I want an answer. How you doing love? Ei, I'm talking to you, shake her hand oh and then she (gestures turns head smiles) you know" (Relative CH2)

Similarly, relatives in CH1 also reported enjoyment from interactions with their resident and emphasised the importance of non-verbal communication. They spoke about their relationships with the residents since care home placement and how they spend their time with them at the home. Relatives enjoyed interactions with the residents and particularly moments of clarity, were referred to sharing humour and laughter:

"They say she's in the last stages of dementia and... (laughs) my husband, (Robert) he's my mam's favourite from the start. So we came,, Robert and mam sat in the corner. I said look who I've brought with me mam. Robert's English so she spoke English, mam's looking up and Robert, she said 'Oh Robert, I haven't seen you in years, how are you matey' and I thought (laughs), this ones got no dementia, you know. She remembered him perfectly, and they spoke to one and another.. It can be very difficult to understand mam because she mumbles, but she spoke perfect with Robert, perfect" (Relative CH1)

"She'll be talking away 'na uh na uh' and then you might a just of what she's trying to say, and sometimes you just say 'oh yeah' and 'that's right' (enthusiastically) just hoping that the answer that you've given is the right one. All you can do is to encourage her to keep on communicating, that's all you can do, and she does it without any problem. She will become more integrated into her dementia as the time goes on" (Relative CH1)

A number of relatives discussed the conversations that they have with their relatives, and how they use different forms of communication, using photographs and tablets to add to their interactions:

"I try and have the same conversation I used to have with her years ago as, as she was. I try showing her photographs, you know, modern technology on the mobile phone. But of course she's got cataracts as well, so I'm unsure whether she can see. She seems to see something, because, you know, she'll start (gestures pointing) so, you know, I hope that she is seeing something" (Relative CH1)

However, relatives in CH1 also discussed how they aim to 'pass the time' for their residents, aiming to provide social interaction and activity. This was because they had concerns that the residents were not partaking in activities and maximising their abilities. They compared life in the community to their current lives in the home and noted a lack of continuation. In contrast to CH2, they referred to aspects of the residents' lives that had been lost when they transitioned into the care home, but understood the care staff do not purposely neglect these aspects of their lives, but simply do not have the resources:

"A day or two will go by and for him, if he doesn't do it then you just lose it, don't you? So when I come, I do get him up and walk him myself They like to have two of them present which is understandable, but you know he will do it and (AC) has decided that she will get him up and do it on her own. It's something you can do isn't it, it's the only thing that you can do" (Relative CH1)

"People come here for him, his friend comes and takes him out for lunch. I wouldn't like to see him here round the reel. I wouldn't like it, even though he does some things, there's a lot of time spare" (Relative CH1)

"It could just be someone to read to them or just the paper, I'm sure they'd like to, I used to do it. They understand a newspaper and just to look through a newspaper, why not give them a newspaper? It's simple isn't it, normal. She was always used to having a newspaper every day, and looking through it" (Relative CH1)

The Relationship between staff and residents

Knowing the resident as an individual & continuity of care

In CH2, staff described their knowledge of the resident as an individual as being fundamental to maintaining the person's well-being. They discussed the changing needs of residents, with some residents now being unable to join others in the living area and having very limited verbal ability. They spoke about their interactions with these residents being supported by their knowledge of them as individuals.

"During the day, the activity staff will go up to see him and they listen to music. There's a channel on the radio that he likes, so we have that on for him. With his well-being, we have information that he came in with, that he gave, and communicated with us, when he had more verbal ability. So, we are able to make the most of that personal information that we have, to hopefully make a difference to his quality of life, now that he doesn't have the verbal ability to tell us" (Staff CH2)

Residents are seen as a part of a community within the home and staff explained how they formed relationships with the residents and got to know them as individuals:

"He is part of the family here; he's been here for years and we have that history with him. We're able to do things in the way in which he preferred when he first moved in" (Staff CH2)

The staff emphasised the benefits of having regular staff providing continuity within the care home as well as having time to spend with the residents, which supports their relationships and knowledge of the residents, their preferences and routines, allowing them to make necessary adjustments where needed to support them best. They referred to residents' enjoyment of different activities and forms of stimulation, recognising that residents sometimes may want to participate and sometimes prefer not, and where residents are able to communicate in other ways:

"We have regular staff here. It's just gently routines; nothing is forced you know, nothing is. If she doesn't want to, we don't. If she's really adamant or, like for meals, and just supporting her she can eat herself but sometimes she gets a bit muddled and I think that is very beneficial, I think, doing a gentle routine. See that routine wouldn't happen at home; routine is really important to her and helps ground her when she's anxious. There is being confused and sometimes she doesn't have that, so it might be a bad day, but a good day is 'I'll tell you this'. Things to stop it, coffee, cakes are good. Again, deflection techniques are good, she's got a huge photograph album and we go through the photographs, that's actually, it brings her back and helps". (Staff CH2)

In CH1, relatives note that some staff are able to communicate with residents well.

"He does have the odd day; he smiles beautifully at the girls {care staff} and they understand him. I'm like 'what was that?' I think that they understand him better than I do, you know. They understand his way, because I can come here and he won't wake at all and you know the girls will say, he hasn't slept last night and that's just what it is" (Relative CH1)

Staff were aware of the importance of body language and non-verbal communication and of finding ways of communicating with the resident through different things that they enjoy, such as colours, touch etc.

"She is very touchy, and in her face too, you can tell with her, you know. Yeah, I mean I find she's obviously very well cared for, and she's got a happy disposition. You can tell when she's not quite a 100%, so yeah considering, it is difficult, because she can't speak. But she is very much, she loves to (touches face), she's very tactile, for some reason she loves my glasses, they're different and she touches those (red/bright)" (Staff CH2)

Time and enablement

Staff from CH2 described seeking to involve the resident in daily tasks where possible, allowing time to give the person opportunity to make their own choices.

"I would say that most of the staff like to involve her. I believe that she still does have the capacity, in some ways, to make decisions. That's variable, but I would prefer to give Alys the chance; I know the other staff would as well. It needs to be one-to-one contact really and allowing response time and making sure she understands the narrative that you're giving and just paraphrase. The most important thing is that she likes eye contact and touch. That is the important way to communicate, is that you're allowing her time to process information and so it depends, the language". (Staff CH2)

Similarly, CH1 staff refer to communication with residents and highlight residents' different means of communication. They discussed how they use opportunities during their care routines to allow the resident to make their own decisions where possible and emphasised the importance of enabling the residents:

"She gets confused but we're still trying to, like you know, would you like fish and chips at meal times or which dress would you like to wear (holds the dresses up). She always chooses her own. But in morning care she feels shy to remove her clothes, but you just have to explain to her, you know what I mean yeah? But still try to make her independent where she can do

things on her own, we like give her the options as well. You just have to do your best yeah" (Staff CH1)

It was recognised that good communication takes time:

"His responses are quite slow as well; they are all different. But with a bit of time, you can almost see his thought process going through. If I was to say 'do you want a cup of tea' and you can almost see the process trying to work out. That way he doesn't get frustrated because it's still his decision. So again, if you're making a decision for him, like does he want a cup of tea, just give him time to answer you. If he doesn't answer you, try and rephrase the question so that it is easier to answer for him, that is what we do. Even in this situation, people still do need to feel that they still have some independence at some point during the day. You know it might be a fleeting recognition of it but it's important" (Staff CH1)

However, in contrast to CH2, care staff in CH1 staff discuss feeling over-stretched, which leads to a lack of time to spend with the residents outside of their care routines. This has a negative impact on the staff well-being, with a number of staff referring to their expectations of how their own family members should be cared for, seeking to balance the expectations of management with their feelings about their care of the residents:

"You don't want to rush people from their beds, but at the same time you feel nervous because they're {the management} *not happy, do you know what I mean? If it was my mum, I would want someone to let her take her time. I don't want to be rushed out of bed into the shower and breakfast so I'm like, why would they? Then we feel guilty about spending time with them and that's the only time we get really" (Staff CH1)*

"We're supposed to do the person-centred, we do try and spend time when we're doing stuff, and then they're {the management} *like 'why is he not ready yet?" (Staff CH1)*

Care staff in CH1 referred to their relationship with the residents being more on a monitoring level. They discussed their role in recognising changes in the residents' well-being and responding, even though, due to lack of time, they were not immediately 'present' with the residents.

"We do go in, but we can't be all the time, because we need to be in the lounge and stuff with everyone. But, if there is anything, if anyone notices she isn't well or like not herself then we have a chat with one of the nurses about it really. Then they know what to do, call a doctor or

something. We do have to write down as well with food and fluid and things and how she is, happy or whatever in the day, so we monitor daily" (Staff CH1)

They emphasised there is always someone 'around', but perhaps not offering the level of interaction they would like.

"Well we're always around, and we write down how much fluids and stuff. But like, we don't have that time to actually sit with them, but when we pass, it's like 'you alright', you know" (Staff CH1)

Staff report finding themselves 'directing' residents, considering acting in their 'best interests'.

"At the moment as her dementia has deteriorated, you just have to help her where she is with what she needs. But I still think she is capable of choosing simple tasks. But, most of the time you have to direct her towards the right one, which is sad yeah". (Staff CH1)

"If I have to make a decision, it is for her best interest and maybe she might not feel like it's in her best interests, but it is, and the only reason I would overrule her decision is that. She can make them but like, if we take her to the toilet and she's covered and doesn't want you to touch her. You know, it is within her best interest for us to clean her, even if she doesn't want you to touch her, you can't leave her like that". (Staff CH1)

Language barriers

CH1 is situated in a strong Welsh-speaking area, and some relatives spoke about the lack of Welsh language being spoken within the home, and how their relatives still retain the ability to communicate in Welsh:

"There isn't enough Welsh I don't think, unfortunately, the importance ... and they {the residents} are able to speak Welsh" (Relative CH1)

Some staff also described a language barrier:

"One problem I find with her because when she feels like conscious of things she starts to speak in Welsh and because I am not a Welsh person I have to be like erm.. can you translate it into English, so I can understand you. But sometimes she doesn't focus, and she's just speaking Welsh and its difficult, and I try saying in Welsh I don't speak Welsh, but they start to speak more Welsh. Then it just gets more confusing for them, you just have to be patient" (Staff CH1)

The relationships amongst staff and between groups of staff

Supportive staff team

Staff in CH2 reported feeling supported by their management team and described a team responsibility for the care of the residents, from the management to the kitchen. The staff discussed having access to, and being supported by, additional resources. Staff compared their current working environment with their previous employment, referring to the home being unique in terms of their relationship with the management and senior members of staff:

"We're supported here, I've worked in loads of homes over the years; it's very, very different. We've got the managers' support here, not just the care home manager, but the owner, we don't go without; it makes a big difference to the working day" (Staff CH2)

"We have good bosses, although Karen is our house manager, her role differs, you know. She doesn't just stick to, and you know Alan (home owner) is as well, a good boss, so if you get it from the top, it filters down" (Staff CH2)

Care staff in CH1 did discuss having supportive relationships with one another and having an understanding of working patterns and routines:

"We have each other's backs, you can't just be by yourself and do everything, you're supposed to have a team. Especially at the moment, we have a good team" (Staff CH1)

Relatives from CH1 also see staff working together. For example, one relative commented how the night staff and the day staff work well together and report changes in the residents:

'The night shift did respond to her not sleeping. They let them know, left a note for Sue's nurse, they came to me and said, 'she's not been sleeping, something's keeping her awake'. That side are obviously working well to notice, and they reported it' (Relative CH1)

However, some care staff from CH1 explained they do not always share the same views with other members of the care team regarding care practices. Members of care staff talked about how they deliver care to residents, they compare their own practices and values, with other members of the care team:

"Some of the other staff, they're stuck in their ways, because they've been doing it years, formal and things. I know I've only been doing the job three and a half years, and I will be relaxed around the residents, I will work at their pace. It's like Dee, she hasn't had a shower in two days, but most of the time she just likes to have a wash, and that's what I'm going to

do, because that's what she wants. And they do say, do what the residents wants. I've had so many people knock my confidence, I'm wanting to relax with the residents, but I'm still thinking am I doing this right? Not like, am I doing this right, but am I doing this the way people would want it, or I'm not as good as other people?". (Staff CH1)

Pressure from management

In contrast to CH2, there were clearly differences in staff views on care provision, and feelings of pressure from management, who were seen as having unrealistic expectations at times.

"Like I said, I love my job, yeah, but it's just, there's not many, but there's certain members of staff that expect you to work so quickly. I'm like no, I'll work on my pace". (Staff CH1)

Care staff in CH1 refer to the 'management' often; how they underestimate their workload, and perhaps not having a shared understanding of the needs of residents living with dementia. They discussed the mismatch between the management's expectations and the reality of the situation, creating an additional burden:

"I just think management, I feel like it's not fair to say that they criticise you for everything.. But, you never get any appreciation for anything that you do. With time, it's obviously different on the general side, but these people have issues, and just dressing someone is sometimes really hard, because they're very resisting, but they don't understand. They understand about dementia, but they don't truly understand how difficult it is, than nursing" (Staff CH1)

"They expect you to do them all dead fast but, with the hoisting, it isn't going to be done fast. It's a lot of pressure to do stuff on time, you know? It's a person, not an object, it would be nice to just have that bit of extra time, not them putting pressure on you" (Staff CH1)

The care staff in CH1, discuss the training that they receive, and how they are conflicted in seeking to put into practice approaches which involve spending time with the residents:

"It's like the mattering stuff. We have to do it, but then they want to know then why you're sitting down, or, like, if they're not up or dressed in a certain time. So, they want us to spend time with them, but then we can't because if we do, then we just get told off for sitting down or something or if they're still in bed"

In contrast, staff in CH2 reported feeling assured that they are not under time constraints:

"We've got the time here. If somebody goes into Cath and she's not right, they're not under a time limit on getting her up. It can take an hour and a half to get Cath up, but it doesn't matter or it takes half an hour, that's fine too. Whether as in other places I've worked, they're not bothered are they just shooing them along" (Staff CH2)

Staff in CH 2 also referred to the support they receive from the management team, support within their roles and resources. The staff reported feeling that they were able to discuss matters with other members of staff and management. They felt valued and that their input is important, regardless of position.

"Well he's amazing, he is so good, and I do find that here, everybody is able to put their input in, even the carers, cleaners you know. If you see something not right about.. you can discuss it and nothing's dismissed. What you say, it is taken on and sometimes we can, you know, discuss and nothing is dismissed what you say, it is taken on and if the residents talk to us, you know, we can discuss it and it's not discussed in the living room you know. Everybody supports everybody here, I support the carers, the carers support me and even the kitchen" (Staff CH2)

"I've worked for Mathew for 26 years, so I know I can always ask if there's something I need. And if I'm not going to see him and I'm outside of work I can give him a call or something; so he's always there, you know. We just say can we have a word, can we have this [care home owner] and he's like 'what do you want now' (laughs) but we get it and he lets us have, whatever we need we just ask" (Staff CH2)

Implications of relationships for Well-being

The network of relationships in the Homes appeared to have a strong influence on the well-being of residents, relatives and staff (see Figure 7.3). Tensions in relationships – most evident in relationships between relatives and staff and between different staff groups in Care Home 1, could lead to distress for relatives and staff, and provide a less firm underpinning for the well-being of residents.

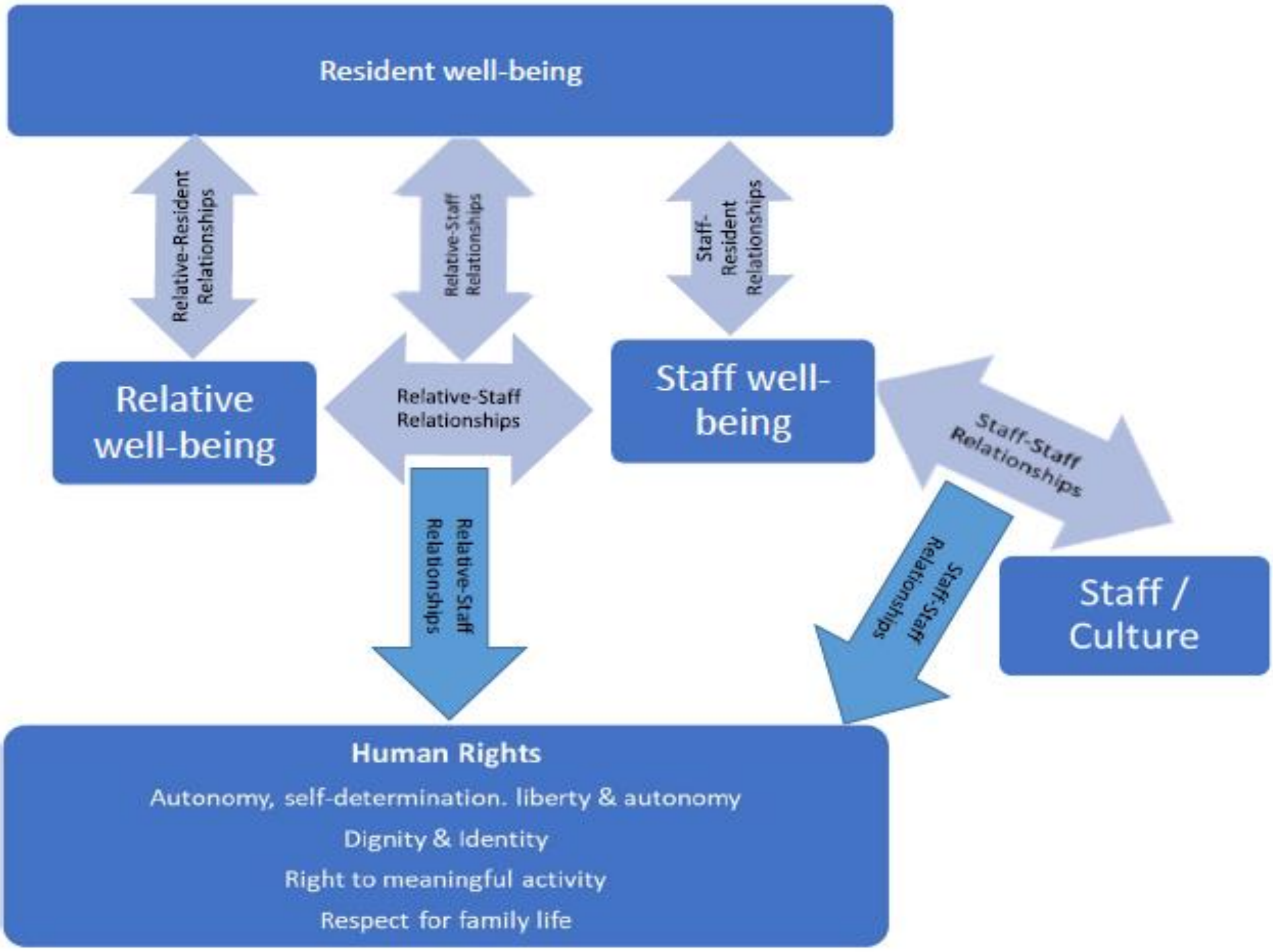


Figure 7.3 The impact of relationships on well-being and Human Rights. Well-being of residents, relatives and staff is supported by the strength of their relationships. Tensions in these relationships have the potential to reduce well-being.

Residents' well-being

Relatives talked about the benefits to the residents of living at the care home, referring to a sense of security and opportunities for interaction:

"At home she didn't sleep very well. At home there's always things going on, clicks and sounds, I would say that made her uneasy or panic. It's a security thing, isn't it, and having people around her; she was terrified and up in the night. But once they know they're safe.. Now she is content in her environment. She is more at peace where she is, and she sleeps quite well. The staff don't have any problems" (Relative CH1)

"She keeps herself busy. She's allowed to wash dishes here, she cleans brasses and sometimes she'll have a duster in her hand and she's dusting. In herself, she's happier here than she was at home, you know. At home, you know, she would just sit, and she would just sit all day, but here she's interacting with lots of people and she's eating better since she's been here, much better yes" (Relative CH1)

Relatives from both homes explained how improvements in physical well-being were clearly visible since admission to the care home:

"Her face has filled out, and her neck, the difference. The day I brought her she ate all her lunch and then her pudding". (Relative CH1)

"Since she's been here, she always looks healthy, whereas, when she was living at home, she didn't look after herself properly and could look unwashed and uncared for. I was there every day; there's only so much you can do. We arranged carers to go in, but she wouldn't let them do anything". (Relative CH2)

"She's well looked after. The staff do so much for all of them; I always joke I'm booking my bed (laughs). She always eats you know, always, so if she isn't, that's when we know something isn't quite right". (Relative CH2)

The high standard and accessibility of care was also seen as contributing to physical well-being:

"Yesterday she wasn't well, and I felt she felt particularly hot. I went to see the nurse, I said 'she feels hot to me'. She wasn't herself at all, you can tell, can't you? She came straight back (nurse) with a thermometer, came straight back, gave her some paracetamol, that isn't an issue really" (Relative CH2)

Some relatives in CH1 reflected on a decline since care home placement and the impact of lack of interaction and activity on well-being:

"She's gone too far to do anything, so they just look after her now. But I think it's a shame, she doesn't have more interaction. But maybe some people can be a bit aggressive, can't they? I don't think she ever has been, a bit of shouting maybe. She doesn't take much interest in anything really, but plays with her blanket" (Relative CH1)

"Sometimes he doesn't like the food or doesn't come out of his room, which isn't their fault. But he is lonely, and they've said they haven't got the time to sit and talk. With the staff, I think for his sake and for them, they need to have more of them and I think when somebody's living long term, as in forever somewhere, it's part of their quality of life that someone should be able to go and talk to them or take them out for a walk. It is important for him that he is able to get up and walk, even to the toilet and back (Relative CH1)

However, staff members in CH1 referred to the impact of family members on the well-being of the residents:

"Well usually he's okay. He smiles and chats. Sometimes his daughter comes; he likes that, you know. She walks him up and down and round the home, he likes to be on his feet. He isn't safe on his own though, so he can't". (Staff CH1)

"Cathy will have her food and a cup of tea and treats in-between, you know. We leave stuff her daughters bring in on the table so she can pick, she was underweight when she came" (Staff CH1)

A key factor in maintaining and promoting residents' well-being at CH2 was the knowledge staff had acquired of residents as individuals:

"She likes Rice Krispies, and so what if she's having it for lunch and dinner? There's milk in that, there's calcium in that, it's getting fluids and getting something down her. You know for a fact that she won't drink the 200mls, she'll drink a 100mls and then throw the rest of it away. But if you put a 100mls in the beaker, she will drink it all and then another 100mls she'll drink that as well. I think it's over facing a bit and you get to know them through person centred things" (Staff CH2)

"Just supporting her, she can eat herself but sometimes she gets a bit muddled. I think that it's very beneficial, doing a gentle routine, see that routine wouldn't happen at home, routine is really important to her and helps ground her when she's anxious (Staff CH2)

Relatives' well-being

The positive relationships and social environment of CH2 clearly had a beneficial effect on the well-being of relatives, with the home providing a social network and supportive environment for relatives. One participant said:

'I feel as though I belong here, I find it very good and when they have sing songs, I join in that and the quiz'. (Relative CH2)

Participants discussed the home inclusivity providing an important avenue for socialising

'It's my social life coming here to be honest, I come here and if Martha wasn't at the home, I wouldn't have half the social life, well I wouldn't have one at all'. (Relative CH2)

Relatives also explained how the care the residents receive at the home directly influenced their own well-being:

"They've done a brilliant job with mum and it's certainly helped me, you know, and it impacts the rest of the family too; if you're alright, they're alright. They just really have been an absolute godsend to us. I don't know where we would be without them" (Relative CH2)

In contrast, the gaps in communication from staff to relatives in CH1 at times led to reduced well-being. One participant described a visit, when her mother-in-law had heavy bruising to her face, which they had not been made aware of prior to visiting. The participant discussed how they found this situation difficult and upsetting, resulting in her husband (the resident's son) being unable to stay for the duration of the visit.

"I came in, I could see a bruise forming on her head. I thought 'Christ has she fallen or? I asked, and they said nobody saw anything. When I came here on Sunday with (her son) he was quiet and he was upset, he wasn't with her five minutes. 'I just can't' he said. She was fine, she was fine, she had no recollection, did she?" (Relative CH1)

Relatives also spoke about how feeling uninvolved in their resident's day-to-day care could be upsetting when their wish to remain involved and being 'around' and open for discussion with the care home staff was not recognised:

"I don't feel as if I matter. It is very distressing sometimes and there's sometimes, well you just take things in your stride and others.."(Relative CH1)

Relatives from CH1 also spoke about the distress they felt as a result of the lack of activities being carried out with the residents in the home, referring to the days being long, and a loss of interaction and continuation (for some) from the activities they engaged with prior care home placement. The mismatch between what they saw as actually happening in contrast to expectations raised by notices and the website was especially difficult:

"There's a programme that is being displayed now in the foyer. I think, well if half of that programme was implemented daily, it would be good. Talk of all of these activities and you know, it didn't happen, but their website was good. I think that's what I would like to see, for the future, not just for my father, but for other people, that will be coming here, because it does pull on your heart" (Relative CH1)

Staff well-being

As already discussed in the Staff-Residents relationship section above, CH1 staff members also felt the weight of expectations – in this case of 'management' for them to complete the work within a set time, and they contrasted this with what would be their expectations for a family member of their own receiving care. Staff accordingly felt anxious about the time they take with the residents during their set 'care tasks' but were conflicted as opportunities to be with the residents outside of the care routines were limited. Guilt could arise from this mismatch between job expectations and the actual working environment:

"You can't rush these people, then it's like, they're.. 'why are you behind' they {management} want to know why everyone's not ready. You don't want to rush people from their beds, but at the same time, you feel nervous because they're not happy. If it was my mum, I would want someone to let her take her time. I don't want to be rushed out of bed into the shower and breakfast so I'm like, why would they? Then we feel guilty about spending time with them and that's the only time we get" (Staff CH1)

For some CH1 staff, the tensions in the relationship with relatives also had an effect on job satisfaction and well-being. Three staff participants in particular discussed how not meeting family members' expectations, despite their efforts, was frustrating.

"Her son is very critical, anything yeah. So it's lovely that he comes to see his mum but at the same time it is as if he's trying to make our job harder, picking on little things" (Staff CH1)

"I struggle, I think people know that. It's just I try and give the best that I can and sometimes and I know that things are changing, but it just isn't enough, for the relatives (Staff CH1)

"Dee's family, I'm taking her to the toilet, they're very chilled out and it is easier. It's nice when you do have a family where you can do things and you don't feel nervous around them. It's just nice when you've got families like that, you don't always feel you're wrong. It's nerve wracking, say some families when you're hoisting and they're there watching" (Staff CH1)

They spoke about the difficulties of their job roles, and how this affects them personally, having set aspirations, and standards of care delivery, but with all the changes in the home, it was difficult to meet these aspirations and standards.

"Big changes. At the moment it's a bit of a hindrance, there's just like work being done here, and work being done there, and nothing seems to be getting finished. I'm sure once it does get finished then we can get settled. So the physical environment seems to be hindering me" (Staff CH1)

Well-being and job satisfaction in CH2 staff appeared high, with staff highlighting the understanding and support of their managers and each other, how this is a benefit to them as staff members, and how it allows them to provide the personalised care to the residents, meeting their individual needs, that is their expectation:

"I don't have any problems at all, because to me that's how I see.. each individual. We are very hands on and we see them throughout the day and everything. But I can say, it's not my needs it's about their needs, you know I'm here to make sure that they're met" (Staff CH2)

"We're a team, ehm.. We've got the back-up of the nurses and then the manager and the deputy manager". (Staff CH2)

For staff members in CH2, being able to approach the care home management is also seen as a real benefit:

We've got the managers' support here; not just the care home manager, but the owner. We don't go without, it makes a big difference to the working day" (Staff CH2)

Human Rights

Relatives and staff were both engaged in considering and enacting how best to maintain and promote the residents' human rights, which was not always a straight-forward or clear-cut process, especially in relation to autonomy, liberty and dignity. Good relative-staff and staff-staff communication were helpful in this, with support for the resident-relative relationship being a key component of the right to respect for family life (see Figure 7.3).

Autonomy, self-determination, liberty and security

It was recognised by relatives from both homes that there could be a tension between liberty and security, with placement in a care home offering safety, whilst not necessarily being the person's choice:

"Yes, they provide the care that we just couldn't. He was wandering the village at 3 in the morning and he was just going out and locking himself out as well. At that time he was being assessed with the aggression and they decided that he was a danger to himself and others. The thing is, he could have been killed and you were frightened in case something did happen to him. A time comes when your freedom can actually be a threat to your life, then that is exceptionally dangerous, he's safer here, much safer" (Relative CH1)

One relative in CH2 felt that the decision to send her relative to a care home was out of her hands, resulting in pressure to find appropriate care placement. The choice (for the relative on behalf of the person with dementia) was not whether or not to live in a care home, but rather which one:

"I think everything's just done isn't it? I didn't want him to come into a care home, but when he fell the hospital said he couldn't come home. So then it's like you don't have this choice and you have to go and find somewhere, you know, or they will send them god knows where" (Relative CH2)

Staff in CH1 recognised that residents would often prefer to live in their own homes, but their care needs are better met by a care home. However, although the home is able to meet their essential care needs, needs for activity and interaction may rely more on family involvement:

"I think she would like to live at home, but wouldn't be able to live alone or just carers coming in. I think at home though you might have more activities and stuff, because here she just sits, but we can't always be with her, because we have everyone else. But her children come though, it's just when they're not around. I just think like because we're busy, but maybe the day is really long for them sometimes" (Staff CH1)

The communal living arrangements of a care home may be a challenge to autonomy. One staff participant from CH2 discussed factors of living in a shared environment and how they negotiate different resident's preferences:

"I always think we work in their home, that's the way you have to look at it. The only thing you can say if Jerry was watching the telly, and what if she didn't want to watch the telly? If she said she didn't want to, we would take her into a quieter area, there are other options. But it is a shared lounge and we do put a bit of music on..." (Staff CH2)

Relatives in CH2 discussed how staff and relatives sought to maintain and support independence, respecting the person's individuality:

"They're good with working round her needs, not cancelling her needs and her as a person. They did in the past have to lock the door a few times before taking meds and they tell her, one of them will go with you, or go in the garden with you know. We all have a laugh and cheer her up and things, she's been used to being independent" (Relative CH2)

Dignity and Identity

Staff in CH1 discussed difficult situations, where they have to make decisions within the residents' best interests, where the resident does not wish to receive care:

"They should be the same, I think we do our best here, we don't do anything they wouldn't want really. But like it's hard when they refuse to be changed, because it's abuse to leave them wet yeah? Just have to talk to them through these things, because it's for their best interest" (Staff CH1)

For this staff member there is a challenge in providing personal care with dignity, for someone who is resistive, in order to avoid the indignity of a person being left incontinent.

One relative from CH1 discussed how she felt it could be counter-productive if a refusal by the person to accept care was taken at face value, discussing the differences between 'encouraging' and 'forcing':

"That's what was wrong with her and not eating and them not forcing her, in a way. But a lot of carers say, we can't force them. But I know not forcing them (hand gestures physically) but say 'c'mon, you must eat'. I don't see that forceful, but it's the bloomin rules isn't it" (Relative CH1)

In CH2, staff members discussed potentially difficult situations where they went against the advice of official care assessments to care for a person in bed because that would deprive that resident of the benefits the care home could provide, in terms of having social interactions with others. Determining best interests was not straightforward:

"If she was really adamant, we couldn't drag her off the chair, we would document it. Social services will say, she should be nursed in bed, but that's taking away her life. It's a fine line you know, because people get a lot from being in a lounge with others. And if they have a couple of days ill in bed, they start to become withdrawn". (Staff CH2)

Some relatives from CH1 spoke about the dignity of their parents being compromised at times. For example, one relative referred to the staff discussing residents' care needs in public areas of the home:

"It's not just for mam but I do think that their dignity sometimes isn't respected, and I think... you know, I have in the past, heard staff chatting about them (residents) and you could hear it

was inappropriate. We don't know what they know, and talking about the person as if they're not in the room" (Relative CH1)

Where residents were unable to make their own decisions, care staff discussed how they are placed in the position of making decisions on their behalf. In doing so, they sometimes refer to their own family members and how they would want them to be cared for:

"You just have to go with your gut, and, like, what you would want for your mam or nain..That's how I do anyway. And she's just not able to make them, because she wouldn't look after herself no" (Staff CH1)

However, making decisions based on what staff would wish for their own family members may run the risk of putting the particular individual resident's preferences and wishes at risk.

Staff participants from CH2 explained how rights are maintained, as residents are seen as members of a wider family, and their rights are promoted through continuity of staff, who have relationships with the residents as individuals, maintaining their identity despite the progression of dementia:

"He is part of the family here; he's been here for years and we have that history with him. We're able to do things in the way in which he preferred when he first moved in, so I think his rights are maintained that way. Also, he sees the same faces, familiar faces that he knows and who know him, his rights are promoted in that way" (Staff CH2)

A relative from CH1 referred to the lack of Welsh speakers working in the care home, and how this limits Welsh residents, who may be unable to communicate verbally in English:

"There isn't enough Welsh I don't think, unfortunately, the importance ... and they're able to speak Welsh" (referring to residents ability) (Relative CH1)

This could impinge on the person's identity, as well as leading to issues in personal care through communication difficulties.

Right to meaningful activity

Relatives from CH1 spoke about the lack of meaningful activities for the residents, comparing their opportunities at home in their communities with care placement. However, they were mindful that activities require staff members and time to facilitate safely:

"He would be gardening (at home) and there are some gardens here, I only hope that something will happen with the gardens. I know that it is also a responsibility taking them

out, because my dad has this shuffle. But you do feel that is where you need to put in money, to facilitate that kind of activities. Also, maybe they would, then tire in a different way and I think that everything comes back to the finance" (Relative CH1)

One staff member referred to recognizing a decline in one resident and suggesting the possible link with the care home environment:

"Well he's normally a happy guy anyway, but not as much recently but normally yeah. Maybe it's just a decline or.. the environment, because he can't just pop out. He's happier when he's active." (Staff CH1)

A member of staff in CH1 explained how she didn't feel that they were purposely breaching the residents' human rights, but, like a number of relatives, felt that the level of activity offered should be improved:

"I don't think we're breaking them but it's like, maybe he would be doing more stuff if he was at home. Paula (Activity Coordinator) is fab, but there's just one (AC) and then she has to do everyone" (Staff CH1)

Staff members in CH2 referred to activity with the residents and assessing the risks and finding ways of promoting opportunities for residents, where possible:

"Just by speaking to her, asking her, I don't think there's anything that we wouldn't or allow due to safety, we would find a way around it you know there's… I know sometimes we have to say we can't do that, but we will try and accommodate" (Staff CH2)

They also refer to residents who are unable to attend the living area, and how they continue to provide meaningful interaction, and this does not deduct from their rights

"Well with Brynley, he is bedbound, but he isn't alone. He isn't just left, the girls go in and natter to him, which I think brightens up his day. Just because he's got advanced dementia doesn't make his rights any different to anyone else in the home. Yes, he could be bedbound, and just in his room all day, but as I said, activities go there; we go in, put his favourite music on" (Staff CH2)

Respect for family life

In previous sections, the importance of the openness of the home to family involvement and the warmth of the welcome has been highlighted, and underpins a core human right:

"I can come in half eight, nine o clock at night sometimes you know. Okay, I've knocked on the door if it's been locked. Usually when I'm going home I say to one of the girls 'oh do you want to lock up, I'm going'. I pop in and out and I'm always made welcome and whoever you see they're always 'you alright' (smiles) 'hiya, you okay' and they always make you feel welcome, and often pop and get you a cup of tea" (Relative CH2)

"They can come whenever they like;, they can chat whenever they like and incidentally, Anita has the opportunity to go home and she likes that." (Staff CH2)

Where, perhaps due to lack of availability of specialist care provision, people with advanced dementia are placed in facilities at some distance from their families, this right is threatened. One participant discussed how her mother's previous care home placement was over an hour's drive from her home and family was problematic, and the difference being placed closer to home has made to her:

"She wasn't even eating herself at the other home, we had to physically try and feed her. But now she's actually eating again, so that shows, she's in a better environment for her, she's more contented" (Relative CH1). She had lost a lot of weight and I don't know if she couldn't (feed herself) or she was just home sick (at the previous CH). She began to cry, oh she was sobbing, and I was like, don't cry because you'll make me cry. Don't cry, I said, c'mon just eat now, you're close to us now, we can come regularly. Through tears 'Hiraeth' she said {closest English word longing}

Discussion

Summary of findings

The aim of this study was to explore two main issues (Stake, 2005, p.448): the well-being of residents with advanced dementia, family members and staff and the perceptions of human rights in this context. The main findings highlight the importance of relationships in care provision and well-being for residents and caregivers, formal and informal, and draw attention to some of the dilemmas faced in respecting and upholding human rights.

The initial, intrinsic, analysis of each case separately suggested that staff in the two homes – despite differences in age and length of time working in the home – had similar themes underlying their interview responses. Both sets of staff discussed communication with residents, and the importance of their knowledge of their residents in monitoring and responding to their needs. They talked about acting in the residents' best interests and offering choices and opportunities. Both sets of staff described the culture of their respective homes, but here the difference in experiences became most evident. Care Home 1 staff were under time pressure, could not provide the activities they would like to do, and noted differences in attitudes amongst the staff. In contrast, Care Home 2 staff described being part of a cohesive, supportive team. The greater well-being of Care Home 2 staff identified in Chapter 6 may relate to this key difference in the working environment.

Although there was some overlap of the initial themes generated from the interviews with relatives in the two care homes, especially in relation to the emphasis relatives placed on their own interaction with their resident, there was a clear difference in their relationship with the homes. In Care Home 2, relatives clearly felt part of the community of the home, whereas in Care Home 1, family involvement and relative-staff communication could be more problematic. Relatives were aware of the time pressures on staff in Care Home 1 and were aware of how this impacted on activities and going beyond residents' basic needs. The lower strain reported by Care Home 2 relatives (noted in Chapter 6) could be attributable to the powerful sense of belonging, and of their own needs being met, evident in the qualitative interviews. This contrasted with the more mixed, at times conflictual, feelings reported by Care Home 1 relatives.

The cross-case analysis took as its starting point the network of relationships within the homes, beginning with those forming the well-established Triangle of Care (RCN, 2014; Woods et al., 2008, p.14), but adding relationships between staff, as these had also emerged as prominent in the initial thematic analysis.

Staff-relative relationships in Care Home 2 were characterised by trust and involvement, with responsive staff and a good flow of information. Tensions were evident in Care Home 1, with staff frustrated by not being able to meet their own expectations and aware of relatives' anger and criticism. Relatives here did express sympathy and concern for staff, whom they saw as over-worked and having too little time to meet the range of residents' needs.

In both homes, *relative-resident relationships* had positive aspects, with relatives providing interaction and socialisation, using creative means of communication, and having times of shared enjoyment. In Care Home 2, relatives felt supported by the home in doing this, whereas in Care Home 1 there was a sense that relatives felt they were having to fill a gap in the Home’s provision of activity. Aspects of loss were described, but in Care Home 2 the possibility of some continuity of life was recognised, especially in relation to the family.

Staff-resident relationships in Care Home 1 were also affected by the time-pressures staff felt under. They saw themselves as ‘monitoring’, not always having the time to engage with residents as fully as they would wish. Whilst they felt they knew their residents well, in Care Home 2 the continuity of staff and the duration of residents’ time in the home meant that relationships had been forged before dementia had advanced. In both homes, staff had developed skills in communication, although in Care Home 1 some difficulties were reported in providing care using the person’s preferred language.

Staff-staff relationships were strikingly different between the homes. In Care Home 2, staff feel supported, by each other and by the home’s management. In Care Home 1, although staff report some support from their colleagues, there are differences in attitudes between staff and a sense of unrealistic expectations from management, leading to the time pressure frequently referred to. Staff in Care Home 1 found the mismatch between what they are encouraged to do in training and what they are able to do in practice frustrating and disappointing.

These analyses of relationships in the Homes enabled the in-depth exploration of well-being of staff and relatives, as well as that of residents.

The impact on *staff and relative well-being* followed directly from the network of relationships described. Care Home 1 staff experienced threats to their job satisfaction and well-being, feeling unable to meet the expectations of relatives, management and, importantly, themselves. Relatives and staff in Care Home 2 felt part of ‘one big family’; relatives were very satisfied with their resident’s care and reported positive well-being. Relatives in Care Home 1 felt upset and distressed at times, wanting more involvement, wanting to see more activities and better communication with the home. These qualitative findings mirror directly the quantitative results from Chapter 6, where in Care Home 2 staff well-being and relative’s satisfaction with care was greater and relative strain less than in Care Home 1.

Resident well-being presents a more mixed picture, again reflecting the questionnaire results presented in Chapter 6. In both homes, residents are seen as safe and protected, compared with their situation before admission to the home, and fundamental needs are met. Some residents have improved in their physical state since admission. The interaction with visiting relatives also contributes to residents’ well-being in both homes. There are differences in reported well-being, attributed to the comparative lack of activities in Care Home 1 and staff in-depth knowledge of residents in Care Home 2, which were not evident in the quality of life evaluations reported in Chapter 5.

Human Rights emerged as a clear theme in the cross-case analysis, although with some inter-dependence with relationship issues. Staff in both homes discussed acting in residents' 'best interests', a much-used phrase which often refers to impinging on a person's autonomy in the pursuit of safety and security. The continuity of care and in-depth knowledge of Care Home 2 staff and their good communication with relatives was seen as enhancing the extent to which 'best interests' could be discerned. In both homes, there was awareness of situations where 'best interests' would be in conflict with the person's refusal or stated preference. In identifying discussion of four specific areas of human rights, this study has succeeded in building on Study 1 (Chapter 4) where the emphasis was on human rights primarily as avoidance of abuse. Here, issues relating to 'Dignity and Identity', the 'Right to meaningful activity' and 'Respect for family life' were identified, in addition to the domain of 'Autonomy, self-determination, liberty and security' which is at the core of the 'best interests' issue.

The culture of care

The findings from this collective case study have highlighted differences in the culture of care between the two care homes studied. Organisational culture is not a new concept, emerging as a field of research in the 1970's, with the aim of studying the role of leadership and management approaches within organisations (Bellott, 2011). Schein (1990) defined organisational culture as a learnt behaviour exhibited by a group, developing and adapting to change, in response to situations experienced over time, and shared with new members as accepted norms, values and behaviours. The group is strengthened through survival of the external environment, solving problems and shared intense experiences. The perceptions, thought processes, and behaviours the group share ultimately becomes the culture of the organisation.

The significance of cultures in care homes and dementia care has long been recognised as a fundamental aspect in quality care provision (Kitwood & Bredin, 1992; Kitwood & Benson, 1995). Kitwood contrasted the new and old cultures of dementia care, investigating the underlying beliefs and behaviours in practice. Kitwood emphasised the importance of authentic contact between PLWD and their caregivers with regards to developing relationships through everyday interactions. He suggested that interactions between PLWD and caregivers had the potential to uphold and promote personhood or undermine it. He suggested negative interactions were not deliberate but formed as the result of the prevailing culture.

Kitwood (1997) introduced an illustrative typology of care environments, known as type 'A' and type 'B' care environments, focusing on organisation style and culture. In type A, a firm hierarchical structure exists, where workload and orders travel downwards. Information and suggestions from 'below' are very rarely seen and the managers in the organisation take responsibility for the administration and are out of touch with the daily experiences of the staff and residents, creating a feeling from the staff that they are unapproachable and unsupportive, forming an 'us' and 'them' division.

In type B, the authority of the management team is implemented differently, as they enable and support staff to carry out their roles, creating a sense of mutual respect and trust. Type B settings, therefore, minimize the 'us' and 'them' divisions, creating an open environment with well-developed relationships and appreciation for each other's knowledge and skill. The type A culture is unaware and therefore insensitive to the experiences and feelings of the staff, where they continue to carry out their job roles at a great personal cost. Type B staff are appreciated regardless of their role, and able to meet the requirements of their role as carers, without great personal cost (Brooker & Kitwood, 2019, pp. 124-126).

Both Care Home 1 and Care Home 2 relate to these types, setting up a contrast between opposite poles. Care Home 1 may be best described as type 'A', where a hierarchy of power exists, and the management team are in a superior position, based on the role, with power held at the top, and the experiences of the frontline staff rarely being heard. Unaware of the daily challenges faced by the care staff, the management team are unable to provide the appropriate support. Care Home 2 relates to type 'B' where the role of the management is not fixed to the administrative running of the home, encouraging the relationships of staff and residents, promoting openness and communication, creating a community for all (Brooker & Kitwood, 2019 pp.124-126). The values and behaviours that organisations create filter down, which ultimately effects the residents, relatives and staff.

In Care Home 2, there was a shared purpose and value for delivering person centred care, and a permission for the staff behaviour to be consistent with the value of the care home ethos. Also, open communications, between the management, staff and families, provided more opportunities for staff to reflect and acknowledge the emotional and physical impact of providing care at that level. These open communications and relationships could have contributed to their sense of well-being and resilience, and time in employment, suggesting lower staff turnover.

Where the purpose and values of the care home are not shared, this has an impact on care practices and the particular community (Killett et al., 2016). According to Care Home 1 staff, the expectation of delivering person centred care is present on induction but does not transition into the floor practices. As a result, staff members are trying to provide the ‘best’ they can, with the resources they have, whilst managing families’ expectations and compensating for the organisation’s shortfalls. A shared purpose and understanding of values and residents’ needs is required to exist across the home across all levels of staff, to be evident in articulated practices and in management. However, demonstrating shared values is not enough, to create and sustain positive cultures the values must be embedded, and the resources provided to the workforce must match the values (Killett et al., 2016; Scott-Cawiezwell et al., 2005).

The care environment

Previous studies have highlighted that environment and social relationships at work impact staff well-being (Kadri et al., 2018; Killett et al., 2016; Kramer & Schmalenberg, 2008). Care Home 1 staff discussed their work environment, highlighting the renovations at the home, which led to navigating large areas and residents being relocated to temporary areas throughout the day. Care Home 2 staff referred to their single communal area as a positive space, bringing the home together. In addition, in Care Home 2 the manager was readily accessible to support staff, adding to their support, should it be required. Greater manager support and peer support has been identified to increase well-being and job satisfaction (Albers et al., 2014). Clear differences exist in the layout across both homes, residents in Care Home 1 had access to multiple living areas, whereas in Care Home 2, all the residents shared one large living space, for all residents, possibly adding to the sense of community and support for staff. However, for staff in Care Home 1, needing to cover several separate locations within the Home could have possibly added to their work demands.

With regards to their relationships with their colleagues and management, Care Home 1 staff referred to their lack of support from management, differences in care attitudes, and for the most part, did not value support from one another. The staff referred to differences in views and attitudes; previous studies have found care staff burden associated with a resentfulness towards others, who are attempting to provide higher than the basic minimum (Kadri et al., 2018; Killett et al., 2016).

Time pressure and the risk to person-centred care

Care Home 1 staff discussed their relationships with the residents, which were centred around personal care and monitoring, acknowledging that they did not have the 'time' to provide further interaction. They highlighted their desire to provide higher than basic care needs, but simply not having the resources. These findings are in line with previous findings (Kadri et al., 2018; Ward et al., 2008), where care staff faced organisational constraints, forcing care staff to provide task orientated care, where their own personhood, and their identity as a good carer, was challenged. As a response to the pressures, staff found ways during personal care to provide interaction and provide residents opportunity, for example, to wash and dress somewhat independently, which has also been highlighted in previous research (Ward et al., 2008). Despite this, they were still anxious about the time it would take to complete their given tasks. They discussed how tasks are performed in a minimal way, where they withdraw once the basic tasks are complete, and any opportunity to connect for both staff and resident is abandoned (Cooper et al., 2018; Killett et al., 2016). In addition, they discussed care routines where they would like to empower residents through opportunity and offer greater independence, (e.g.self-washing), also being reduced due to the 'lack of time'.

In contrast, staff in Care Home 2 valued support from other staff members, they felt reassured and confident within their roles, and supported by their management. They placed emphasis on supporting each other, regardless of job role, citing 'we're a team here'. The staff talked about the ease of working with residents, having had the opportunity to get to know them well as individuals. Brown (2016, p.249) suggests that contributing to a person's QoL requires individual knowledge about the person. Although QoL can be influenced, it is about knowing that the individual may enjoy music, but only played at a certain level, highlighting the need for attention to the finer details. The staff in Care Home 2 acknowledged and were appreciative of the support they received to deliver individual and person-centred care, specifically referring to providing personal care 'it takes as long as it takes'. They referred to utilising skills that they had learnt (they had been involved in the 'Creative Conversations' project; Windle et al., 2019) to promote their interactions with residents and everyone's understanding, that every day will be different for the residents.

Further, they appreciated the opportunity for open communication with the management, and the right to request additional resources, in support of their roles.

Previous research found work expectations of organisations conflicting with the moral imperatives of the care staff challenges self-worth of carers and identity (Cooke et al., 2018; Cooper et al., 2018; Kemper et al., 2008) and reduces sense of self-accomplishment (Kemper et al., 2008). Additionally, where their successes are simply measured in the completion of set tasks, their opportunities for learning as well as their own dignity are denied (Bowers & Nolet, 2011; Scales et al., 2017). Furthermore, they struggled to maintain a balance between the expectations of the organisation, residents and their families and their personal goal to provide genuine care. Despite the challenges, they discussed the value of their work and spoke passionately about caring for people living with dementia.

Family involvement in care homes

Care Home 1 staff referred to their relationships with families; some were positive, where they felt valued as carers, which also provided a sense of reassurance and confidence, whilst carrying out their roles. However, they recalled a number of families who they felt were unhappy with the care provision. The staff felt families held them responsible, as they had no understanding of the demands placed on them by their management, which they believed, reflected badly on them as carers. Previous research suggests an understanding of each other's roles and responsibilities, will improve and promote family-staff relationships and outcomes for residents in care settings (Bauer 2006; Bauer et al., 2014; Haezler et al., 2007; Wilson et al., 2009).

Despite staff views, families in Care Home 1 were empathetic of the demands placed on the staff, but perhaps due to their distanced relationship this was not formally expressed to them, only their frustrations. The negative perceptions staff believe are held about the care of residents can also contribute to conflict, contributing to relatives' strain (Chen et al., 2007) and staff burnout (Abrahamson et al., 2010). Additionally, where negative perceptions are held by family about care staff, negative perceptions of family can also be held by staff, creating further strain and conflict (Abrahamson et al., 2009) and exacerbate feelings of guilt and distress for families (Bauer et al., 2014).

For relatives of residents in Care Home 1, there were instances where the home had not been the first choice of the family members, with crisis situations leading to emergency placement, and in addition, feelings of uncertainty regarding the care home organisation that took over from the previous care home owner. Care Home 1 staff had many external pressures to contend with, outside of care provision, creating potential barriers to the formation of meaningful relationships, possibly contributing to their strain and creating additional barriers (Killett et al., 2016). Where staff are under significant pressure and where their primary goal is to complete their given care tasks, it reduces their opportunity to build meaningful relationships with families (Park, 2010).

In contrast, Care Home 2 staff referred to their positive relationships throughout the home and beyond, referring to relatives as ‘part of the family’, and valuing their involvement. Study 1 (Chapter 4) highlights the importance of family involvement, the triangle of care (RCN, 2014; Woods et al., 2008, p.14), and the advantages of positive family-staff relationships, and the impact on the residents. Furthermore, the positive impact of family involvement and knowledge, continues to influence the residents’ care positively, when family members are not present (Legault & Ducharme, 2009).

Partnerships between staff and relatives flourish where there is open communication and this reinforces their value in the everyday life of the home, which encourages trust, and mutual understanding of roles (Wilson et al., 2009). Previous research found relationships between staff and relatives promoted greater understanding of the communal nature of living in, working at and visiting care homes, with the focus of such relationships moving beyond the resident to recognise the needs of relatives and staff as individuals, who could all make valued contributions to the home. These relationships found relatives and staff feeling active as a part of a wider community (Wilson et al., 2009) adding to their sense of well-being.

Care home placement can impose new challenges for the relatives, as their roles evolve and take a new direction. However, the care home fulfilling aspects of care provision, such as personal care, allows visits to provide quality time, possibly giving back the most valued aspects of their relationships (Gaugler et al., 2010). Where there is a breakdown in communications between the home and families, and interactions between relatives and the care home staff, this can become a significant stressor for both relatives and staff (Chen et al., 2007; Kadri et al., 2018; Sandberg et al., 2002).

Given the layout of Care Home 1, where residents living with dementia are in a separate area of the home, offering multiple living areas, it is possible that this setting did not support the interactions of the families and staff, reducing their opportunities for communication and support. The layout of Care Home 2, where relatives visited their family members in one shared space, may have promoted opportunities for communications with the staff and other visiting family members. Perhaps having these opportunities may have increased a sense of being part of a community, adding to their well-being, in line with previous research findings Gaugler et al., 2010; Mausbach et al., 2007; Rubin & White-Means, 2009).

Human Rights

Human rights in dementia is not a 'new' concept, yet a rights-based approach has rarely been documented to challenge the practices and policies that do not promote the rights of PLWD (Cahill, 2018 p. 14; Mégret, 2011). Within dementia, as noted by Mitchell & Agnelli (2015), the most influential discourse for PLWD, up until recently, has centred on human needs and personhood (Kitwood, 1997b) and not human rights (Mental Health Foundation, 2015).

Autonomy, self-determination, liberty and security

In this current study, both relatives and staff acknowledged the threat to self-determination in that the residents' personal wishes may be different to the situation that they find themselves in. The findings in this study identify contradictory themes when it comes to supporting the needs of the individual and care home placement. Relatives expressed concern for the safety of the individual, which may have led them to moving into a care home placement, but are conscious of not losing sight of the individual as a free agent (Evans et al., 2016). They acknowledge that living in a care home placement would not have been the individual's personal preference, but highlight the difficult situations faced by themselves as family members, who were left with no alternative by the healthcare services, who had assessed the risk of the individual living at home as too high. However, a number of families discussed that individuals' care needs had increased, and they were unable to meet those care needs at home, including risk to safety and in one case a risk to others, highlighting that it was not the PLWD's decision to move into care home placement.

As stated in the Mental Capacity (Amendment Act) 2019, and the broader Mental Capacity Act (2005), individuals who lack capacity, must be protected under the Act. The Act must be implemented where the individual requires care arrangements (resulting in loss of liberty) to prevent them coming to harm, providing that these restrictions are proportionate, and that harm could be caused by failure to make these arrangements.

The participants' discussion of the residents' right to liberty and security, referring to their own personal safety in being kept at the homes, despite knowing that living in a care home may not have been their relatives' personal choice, is in line with the Act. It is important to note, however, that there was a lack of reference to what would be expected explicitly in terms of human rights. Participants did not, for example, refer to the MCA Deprivation of Liberty (DoLs) or the more recent Liberty Protection Safeguards, replacing the DoLs. (Department of Health and Social Care, 2020).

Families did discuss the importance of the residents' safety and how the care homes were able to provide an environment where residents felt secure, and where family members also took comfort in knowing the residents were safe, and no longer a danger to themselves or others. In terms of the care homes providing a safe environment, they did not refer to residents' safety in terms of setting up personal barriers around the residents, but an environment where residents' needs were supported. For example, in Care Home 2, one staff member refers to the risk assessment procedures and finding ways of working around identified risks to enable the individual to be part of the communal living area in the home, providing opportunities for interaction with other residents.

Family members discussed their understanding of the care homes' procedures, where doors were locked, to prevent the resident from leaving the home alone and to promote their safety. With regards to their discussion around locked and secured doors, they did not refer to these as forms of confinement or as restrictions on the residents' liberty (Steele et al., 2020). Despite this, families did also recognise situations where the protection of their safety could affect the individual, who may not have access, for example to the outside gardens without staff members to facilitate. Although in this instance, families referred to the residents being 'stuck in here'. They recognised that the residents were excluded from opportunities to access the outside gardens; the situation was accepted as unchangeable, in line with previous findings (Steele et al., 2020). Although it is doubtful that a resident with advanced dementia could complain about the policy and procedures of the home, family members are often scared to challenge, due to possible repercussions (Cahill 2018)

The absence of access to gardens for care home residents is an ongoing issue, and it has been noted that in contrast prisoners have scheduled time outside (Alzheimer Europe, 2012). As a result, PLWD become confined through exclusion and reduced opportunities to venture outside the care home, resulting in segregation and discrimination, despite the fact that this may occur indirectly, as part of daily practices and procedures (Steele et al., 2020).

Previous research findings (Steele et al., 2020) suggest that older people's care is prone to risk-averse procedures, creating a culture for minimizing risk which comes at the expense of the PLWD's human rights. To provide person-centred care, the assessments and risk management should involve a balance of potential positive benefits of risk taking, with the negative effects of avoiding 'risk' to maintain safety (Department of Health, 2010). Thus, care home staff must balance a positive approach to risk-taking with their daily practices and procedures, to protect residents in a safe environment (Evans et al., 2018).

In terms of residents' rights being restricted, care staff in Care Home 1, referred to differing opinions between staff about allowing residents to walk around at night, which could be considered an everyday activity. However, tensions existed, where some care staff did not agree that residents should be walking at night-time, whereas other members of staff felt that as their home, they should have the right to walk, despite the time of day. A previous study found where a regular walking routine was scheduled, it reduced night-time walking and behaviours associated with anxiety and restlessness (Wigg, 2010). Creating a scheduled approach to walking liberated both the resident and the staff member, redefining walking as necessary for well-being, rather than a problematic behaviour that needs to be controlled (Wigg, 2010).

The staff in both Homes also discussed many individuals living together and how this may challenge a person's individuality and autonomy, as a result of living in a shared space, and how they attempt to resolve situations that can arise due to differences in preference and needs. According to previous research, residents' experience of autonomy and participation is influenced by their relationships with the staff members and their relatives (Hedman et al., 2019). Staff also discussed where individuals had lost capacity, specifically in Care Home 2, where they had known residents throughout the journey, where individuals lacking current decision-making capacity may exert their autonomy through advanced statements and care planning over a number of years. The previous study by Hedman and colleagues (2019) suggest the relationships with family and care staff are significant in maintaining autonomy, as they will be dependent on the support of others to exert their wishes.

Dignity and Identity

The staff across both homes discussed the complexity and challenges around promoting the residents' dignity and minimising their indignity. They described providing care, despite indications from residents that they did not wish to receive personal care at the time.

Although, the staff understood the residents' right to refusal, and the importance of 'allowing' personal choices, they explained how they could not abandon their care needs as this would be, in their opinion, abusive, for example being left incontinent.
In these situations, the staff discussed taking time to talk through the necessary steps with the resident. Previous research studies have highlighted time as a crucial element to maintain and promote residents' dignity and identity. Previous research found where staff and time capacity are at a minimum, care staff are only able to attend to basic care needs, leaving additional individual needs unmet (Gaither et al., et al., 2008; Slettebø et al., 2010). Research also shows that lack of resources can be a threat to dignity-promoting care (Sellevold et al., 2013; Jakobsen & Sorlie, 2010).

As discussed above, time pressure was a key issue for staff in Care Home 1 who felt anxious about time, and the repercussions of having taken longer to complete tasks, despite being within the best interests of the resident. In contrast, staff in Care Home 2 felt they were not under pressure with time and highlighted the advantages of having additional staff on shifts. Furthermore, the staff in Care Home 2 referred to assessing residents on an individual basis and promoting the residents' dignity and participation as part of the home. For example, staff went against the formal assessment of the individual, which had suggested that the person was to be cared for in bed, to allow them time and social interaction with others in the home in the communal lounge.

Lack of time allocated to staff for providing personal care reduces the person's dignity as well as their autonomy. Examples given by staff in this study refer to washing and dressing the resident as this is the quickest option, as opposed to giving them the opportunity to do this independently where possible. As well as taking from the resident, this practice reduces the staff member's dignity, as they cannot carry out their caring roles in the way in which they would prefer in line with their values and expectations of the role (Kadri et al., 2018; Cooke, 2018; Killett et al., 2016). This led them to feel conflicted between doing what they believe is right for the residents and meeting their management's expectations. These findings are in line with previous research (Windle et al., 2019), where staff also felt an expectation from their management, sometimes imposing a task orientated approach, leaving little time to spend 'just being' with the residents. Similarly to the feelings expressed by the care staff in our study, the staff expressed tension between the expectations of the management to have tasks completed and their intentions to provide the residents with quality time, which created a barrier for them in forming meaningful relationships with the residents (Windle et al., 2019).

Relatives, for the most part, felt the residents' dignity and identity was maintained where the care staff took the time to understand the resident as an individual, and especially where residents had been in care home placement for a number of years. However, in Care Home 1, relatives discussed instances where residents were the subject of indignity and lacked identity. One relative, from Care Home 1, discussed her father using incontinence pads despite being able to walk to the bathroom with the support of two staff members. In her opinion, this support was not possible due to time and low resident-staff ratios which therefore led to her father using incontinence pads to ease the workload at the care home. A second relative in Care Home 1 referred to the discussion of the care needs of the residents between staff in public spaces, detracting from the residents' dignity. Furthermore, relatives discussed the lack of Welsh language provision for residents as first language speakers, also highlighted in Study 1. In line with the relatives' concerns, a member of staff also highlighted the difficulties of understanding the needs and wishes of Welsh speaking residents, as a non-Welsh speaker.

Caregiver–resident relationships are a fundamental part of dignity-preserving interactions, in line with previous findings (Holmerová et al., 2007; Tranvåg et al., 2013) where care staff have the opportunity to promote the resident's individual sense of status and self-worth. However, this was not without its difficulty; faced with complex situations, they found themselves supporting an individual's autonomy even when this was to refuse care, despite their actions not being in their best interests, to maintain their freedom of choice. Supporting a person's positive choices and autonomy is identified as the most dignified option (Tranvåg et al., 2013). According to Evans and colleagues (2016), a dignifying caring relationship, is a relationship where both the individual and staff member interact, and participate in a meaningful way

The right to meaningful activity

Despite activities bringing many advantages, due to the progressive nature of the condition, PLWD at a particular stage may be unable to initiate activities independently and therefore, it becomes the work of those around them to support and facilitate this (Mansbach et al., 2017; Schreiner et al., 2005; Tak et al. 2015). Furthermore, it may be necessary for care staff to assess activities against the individual's capabilities and adapt to the individual's capabilities.

For residents with dementia in care home placements, cognitive limitations and reductions in autonomy create dependencies on care staff to provide activities. As a result, engagement in meaningful activity becomes a reflection of the quality of care provided by the care home. The results from the current research have shown how participants associate daily activity with QoL and well-being of residents. Participants spoke about the advantages, and they also discussed their frustration where they observed lack of activity. One participant especially spoke about the benefits, as her mother-in-law had been a housewife and was given the opportunity at the care home to continue in this role, as she was able to clean brasses, giving her occupation and familiarity and supporting her identity.

Participants spoke about the harm to residents' mental and physical well-being when they spoke about the lack of activity. This is consistent with the National Institute for Health and Care Excellence (NICE) guidelines for 'Mental wellbeing of older people in care homes, quality standard [QS50]

'Meaningful activity is fundamental to the health and wellbeing of the individual accessing care and support. It can help to improve physical fitness, improve mood and help to combat depression and anxiety, combat loneliness, improve the quality of sleep and even reduce falls'

Within care homes, resident inactivity is a common theme and previous research has consistently shown low levels of activities in care homes across a number of countries (Ballard et al., 2001; Cahill & Diaz-Ponce 2011; Hearle et al., 2012; Popham and Orrell 2012; Shippee et al. 2015; Smith et al., 2018; Tak et al.,. 2015). In the UK, studies have found three quarters of care home residents have high levels of unmet needs within occupation and activity (Hancock et al., 2006; Smith et al., 2018), higher than any other aspects. A research study conducted by Towers and colleagues (2016) across a number of care homes using the Adult Social Care Outcomes Toolkit (ASCOT), found occupation and activity low on the Social Care Related Quality of Life (SCRQoL) scale. Similar to our results, the staff involved reported low levels of activity for residents being due to low staff-to-resident ratios and being under resourced, overstretched and unable to meet more than the 'basic needs'.

Care Home 2 staff in contrast, explain the benefits of having time to give to residents, as they are able to promote, where they can, the independence of the residents. In turn, the time they are able to spend with the residents adds to the quality of their relationships and knowledge of the residents as individuals. Importantly here, in addition to their scheduled activities, the residents are able to take part in everyday tasks, such as table-laying.

However, positive aspects drawn from the discussion of activities by staff members found staff looking for ways to provide occupation and activity for residents during everyday tasks, such as washing independently, cleaning brasses, and seeing friends. They also discussed sharing quality moments with the residents, whilst completing their daily tasks. Relatives in CH1 also spoke about wanting to see ‘everyday’ activities being provided for residents, such as being given a newspaper.

With regards to promoting occupation and activity for the residents, results of this project indicate staff would benefit from being allocated more ‘time’ outside of the expected basic care roles, in order to fulfil this need. Previous projects have also highlighted a minimum level of staff-to-resident ratio, which is a significant barrier (Cooper et al., 2018; Towers et al., 2016; Windle et al., 2019). However, care homes already have little control over the funding they receive from outside commissioners, and figures show a decline in funding given since 2010 (Hastings et al., 2015).

Respect for private and family life

A topic which emerged throughout, and has been discussed extensively above, was family involvement and specifically the family sense of welcome into the homes, where they felt enabled to continue to provide care for their relatives and continue with their family activities/relationships as they had prior to care home placement, as also highlighted in Study 1. Families continued to visit their relatives as they had prior to care home placement; in both homes they referred to the open-door policy, where they discussed visiting at any time, in line with the findings of Study 1, and feeling welcomed by the home.

Participants from both homes also discussed the benefits of the residents being in these specific homes, within their communities, promoting their right to family life. The open-door policy allows the relatives and friends of the residents, to provide social opportunities and emotional support. Connections and relationships with family and friends are crucial to well-being (Downs, 2013; Kelly, 2010; Lee et al., 2017). In addition, families provided care homes ongoing support, continuing their roles as partner in caregiving, enabling residents to feel at home and in their community (Hado & Feinberg, 2020). The homes were able to provide a place for family to resume family life, easing some aspects of their caring responsibilities, allowing their time to focus on socialising and sharing meals; aspects that had become strained where families had been caregiving at home prior placement, allowing a shift in their caring roles giving back traditional family roles (Gaugler et al., 2010).

Sadly, during the COVID-19 pandemic, for many, the right to family life has been taken away. The imposed restrictions, where visits from relatives are restricted or banned altogether, reinforces the sense of confinement and segregation experienced by the residents (Steele et al., 2020). For many older people in care homes, family and friend involvement and connections are crucial elements, which enable them to reside in placement. The complexities of protecting older people in care homes, with the rise in COVID-19 related deaths in care home placement, makes the opportunity to maintain contact with family and friends all the more important, as the impact of social isolation is detrimental to QoL and well-being (Hado & Feinberg, 2020; Tan, 2020).

Strengths and limitations

A strength of this study was the rich and in-depth qualitative data from the perspectives of relatives and staff at two very different care home settings. Views from families and staff at two homes, one independent and one part of a wider organisation are reported. In this study, the views and experiences of relatives and care staff from homes with marked differences in the physical and social environments have been obtained.

As discussed in Chapter 6, in Care Home 1 the potential for participant bias must be acknowledged, with several relatives declining to participate due to their views about the change of management of the home, as well as others who lived a distance from the Home.

A further limitation of this study is that, unlike Study 1, it was not possible to seek directly the participation of PLWD living at the care homes, reflecting only the views and experiences of the relatives and care staff. Although it was unlikely that the PLWD would have been able to participate in formal interviews, in view of their advanced dementia, in Study 1 it proved possible through observation and communication methods such as Talking Mats (Murphy & Oliver, 2013) to understand something of their lived experience.

From a methodological perspective, it could be suggested that in relation to both the quantitative analyses presented in Chapter 6 and the qualitative analyses presented in the current chapter, there have been a great many comparisons made between Care Home 1 and Care Home 2. Stake (2005, p.457) cautions against over-emphasis on comparisons: ‘A research design featuring comparison substitutes (a) *the comparison* for (b) *the case* as the focus of the study’. However, he goes on to state (p. 458): ‘When there are multiple cases of intrinsic interest, then of course it can be useful to compare them.' In the current study, with both cases indeed being of such intrinsic interest, the potentially distracting effects of comparisons may have been perhaps mitigated. Although the cases were selected to purposively cover a wider range of contexts than in Study 1, the extent of difference could not have been anticipated.

Finally, ideally the homes would have been re-visited to fulfil participant validation, but this was not possible for logistical reasons.

Conclusion

In this mixed-methods study I have conducted in-depth analysis on data from relatives and staff at two unrelated care homes. I have worked with one home undergoing major changes and during the transition phase, adding to our understanding of external factors which may affect residents, relatives, and care staff within care homes. In contrast, the second home was well established in terms of stability and ownership.

This study reflects, in-depth, the well-being of staff and relatives and satisfaction with care, and human rights, in more detail than the previous study. Although the quantitative results suggested that residents' quality of life, rated by staff and relatives, was similar in the two homes there were evident differences in the relatives' satisfaction with end-of-life care, as well as in relatives' strain and staff well-being. Qualitative analyses allowed further exploration of factors associated with resident well-being and quality of life.

I have built on my findings in Study 1, investigating beyond the initial themes emerging in the intrinsic analysis of each care home separately, which resonated closely with our previous findings in Study 1. In this chapter, by conducting a further analysis of the data, in particular applying a relationship lens, it has been possible to compare the nature of relationships in each case and indicate their implications for well-being whilst also examining in much more depth relevant human rights issues for the residents.

This study demonstrates the importance of building and maintaining relationships in care homes between key stakeholders, residents, relatives, and staff members. This study illustrates a different system of relationships between the two cases, one showing positive feedback systems, which lead to human rights being maintained and promoted; in the other, there were clear tensions, and the pressures were frequently pulling the relationships apart.

I have shown the perceptions of both relatives and care staff members, which provides an understanding of each other's position in terms of maintaining the QoL and human rights of the resident in relation to their caring role, and highlights the need for their relationship beyond their rapport with the residents but with each other, to promote and maintain the well-being and human rights of the residents.

The further analysis in this chapter highlighted both positions, that of the family and the care staff, and their views of their caregiving roles. Care Home 1 staff felt conflicted by the organisation and their caregiving role as well as the expectations of the families. The families in Care Home 1 empathised with the position of Care Home 1 staff and wanted further inclusion by the Care Home and involvement in the care of the resident. However, the care staff felt criticised by the relatives and in instances did not feel confident enough to discuss with some family members. The staff in Care Home 1 felt the families held them responsible for any shortfalls, despite their hardest efforts to provide person centred care.

Despite this the families of residents in Care Home 1, were empathetic regarding the workload of the staff and spoke about ways they could perhaps support the home if they were asked and invited to do so. The relatives were aware of the constraints on the staff, referring to their heavy workloads, with minimum staffing levels and the financial constraints of the care home sector. They understood the staff were under time pressure and reflected on this where there were elements of care that they were not satisfied with, such as the provision of activities.

In contrast, relationships in Care Home 2 had been given the opportunity and the time to form and grow. With many of the residents living in the care home over a number of years, and low level of staff turnover, there were well established relationships between residents, families and the care home. The staff reflected on their positive relationships with the residents and the families, and the care staff felt confident to discuss and involve the families in the care planning. Equally, the families in Care Home 2 felt they were able to approach the care staff regarding the care of their relative and any changes they felt would perhaps be of benefit of the resident. However, the stable layout of Care Home 2 may have supported the community and connections of residents, families and staff, as they came together in one large communal setting. As Care Home 1 was under renovation, the residents, staff and relatives had many additional factors to contend with. Due to the major changes taking place in their immediate settings, they faced regular upheavals, which could have been a barrier for forming a sense of community and more established relationships. A follow-up study in this home once the environment is more stable would be of interest in teasing out the various factors involved.

Chapter 8: Discussion

Addressing the aims of the thesis

The overall aim of this thesis was to explore and increase understanding of quality of life, well-being and human rights of care home residents living with advanced dementia. Achieving personalised, individualised care with a person who is completely dependent on others for care and may no longer be able to verbally communicate their wishes is a major challenge, but essential for the person's human rights to be maintained. In order to achieve the thesis aims, a systematic review and two empirical studies, in a total of four care homes providing care for people with advanced dementia, were undertaken. Chapter 3 provides an overview of the philosophical, theoretical, methodological and ethical considerations underlying the two empirical studies.

Specifically, the thesis aims were addressed as follows:

1) To review and appraise published measures and methods of evaluating QoL, suitable for individuals with advanced dementia in a care home context.

Chapter 2 presents a systematic narrative review, conducted using systematic principles of searching, screening and retrieving peer-reviewed English language research papers. The review was conducted to identify measures which offer a perspective of what might be meant by QoL in advanced dementia. Psychometric properties, quality evaluation, strengths, limitations and accessibility of the six tools were reviewed to identify the most appropriate tool for evaluation of QoL in advanced dementia, and for the current research project. The Awarecare tool (Clare et al., 2012) was identified as a potentially useful observational tool and the QUALID as a relevant and applicable proxy rated measure. These measures were then used in the two empirical studies, with QUALID used in Studies 1 and 2 and the Awarecare tool in Study 1.

2) To explore the lived experiences of residents with advanced dementia in care homes

In Study 1, the researcher explored residents' lived experiences in the care homes, in the context of relatives' and staff members' perspectives of residents' QoL. The residents included were living with advanced dementia in two different homes run by the same organisation. Chapter 5 presents two in-depth case studies of care home residents, Graham (case study 1) and Martha (case study 2) combining both quantitative and qualitative data, as well as observations made by the researcher, drawn from the larger pool of eight residents whose relatives participated in the study. These case studies describe two people with their own personalities with remarkably different ways of expressing happiness, affection, humour and distress. Kitwood's indicators of well-being were found to be helpful in describing how relatives and staff perceived the QoL of the person with dementia. Even with limited verbal communication, the person with dementia remains an individual and, with the support of others, can experience QoL and well-being. Implications for care practice were identified, with, for example, spending time in advanced care planning increasing care satisfaction and having the potential to assist greatly with surrogate decision-making.

3) To explore the perspectives of relatives of residents with advanced dementia }

4) To explore the perspectives of staff providing care for people with advanced dementia }

5) To investigate how human rights of residents are upheld }

These three aims were initially pursued in Study 1, in two similar care homes managed by a single organisation. Qualitative interviews with eight relatives and eight staff members were analysed thematically and presented in Chapter 4. Four themes were identified (see Figure 8.1): well-being; 'the girls'; communication; and human rights. Participants were able to identify indicators of residents' well-being, including physical indicators, food and fluid intake, facial expressions and mood. Further, family members placed importance on moments of clarity 'who he or she used to be' as markers of well-being. Participants highlighted ways of enabling residents to contribute to the social world despite having limited verbal ability, and the importance of recognising different means of communication expressed by the residents, in line with previous research (Astell & Ellis, 2016). The importance of communication between the care staff and family members appeared as fundamental for knowledge, decision making and coordinating caregiving efforts. Indeed, the relationship between staff (described affectionately by relatives as 'the girls') and relatives was crucial, with family members who visited daily seeing themselves working collaboratively with care staff to maintain the quality of life of their relatives and engage in proxy decision making. Importantly, this study identified the lack of discussion surrounding human rights in the care homes, referring to human rights being intact due to there being no indication of signs of physical abuse, with 7 family members stating that their relative's human rights within the care home were maintained.

In Study 2, presented in Chapters 6 and 7, two additional care homes were recruited in order to extend the scope and breadth of the Study 1 findings on quality of life and well-being and, particularly, human rights in advanced dementia. I included a care home operated by a different organisation, as well as a home during a period of major change, increasing the range of management styles and ways of working. A collective case study approach was taken, with two care homes each constituting a case, with relatives and staff perspectives embedded in each. Questionnaires, including the QUALID, were used to augment interview data from the 14 care staff and 14 relatives participating.

Although the two care homes were markedly (and purposively) different in many respects, including physical environment and management styles, there were no differences in demographic variables for participating relatives and their residents between the homes. Staff in Care Home 2 were, however, on average older and had been working at the home for a much longer period of time. Relatives from Care Home 1 reported high levels of strain, compared with levels reported from studies of families providing care at home. Their counterparts from Care Home 2 reported strain levels similar to those found in community settings. Staff from Care Home 2 reported high levels of well-being, well above average for the general population, whilst ratings by Care Home 1 staff were consistent with those reported by the general population. Across the two homes, strain was greater in younger relatives, and higher in those less satisfied overall with end-of-life care. Relatives who visited more frequently felt more involved in decision-making and felt that staff were more sensitive to their needs. Whilst relatives from Care Home 2 expressed general satisfaction with the quality of care provided, families in both care homes expressed dissatisfaction with aspects relating to information regarding their relatives' medical care. In contrast to the between home differences in staff and relatives' well-being, there were no differences between the two homes in the residents' QoL, as rated by relatives or staff although staff rated resident QoL as significantly worse than when rated by relatives.

Qualitative analysis of the interview data produced a set of initial themes that resonated strongly with the Study 1 findings, and so a further analysis of the data was undertaken, applying a relationship lens, producing a set of themes highlighting the key relationships and their implications for well-being, Human rights again emerged as a distinct theme, but in Study 2 could be further unpacked in terms of rights especially relevant to this context (see Figure 8.1). Figures 3.1 and 8.1 show graphically the way in which the Study 2 findings build on and extend those from Study 1, as outlined in Chapter 3.

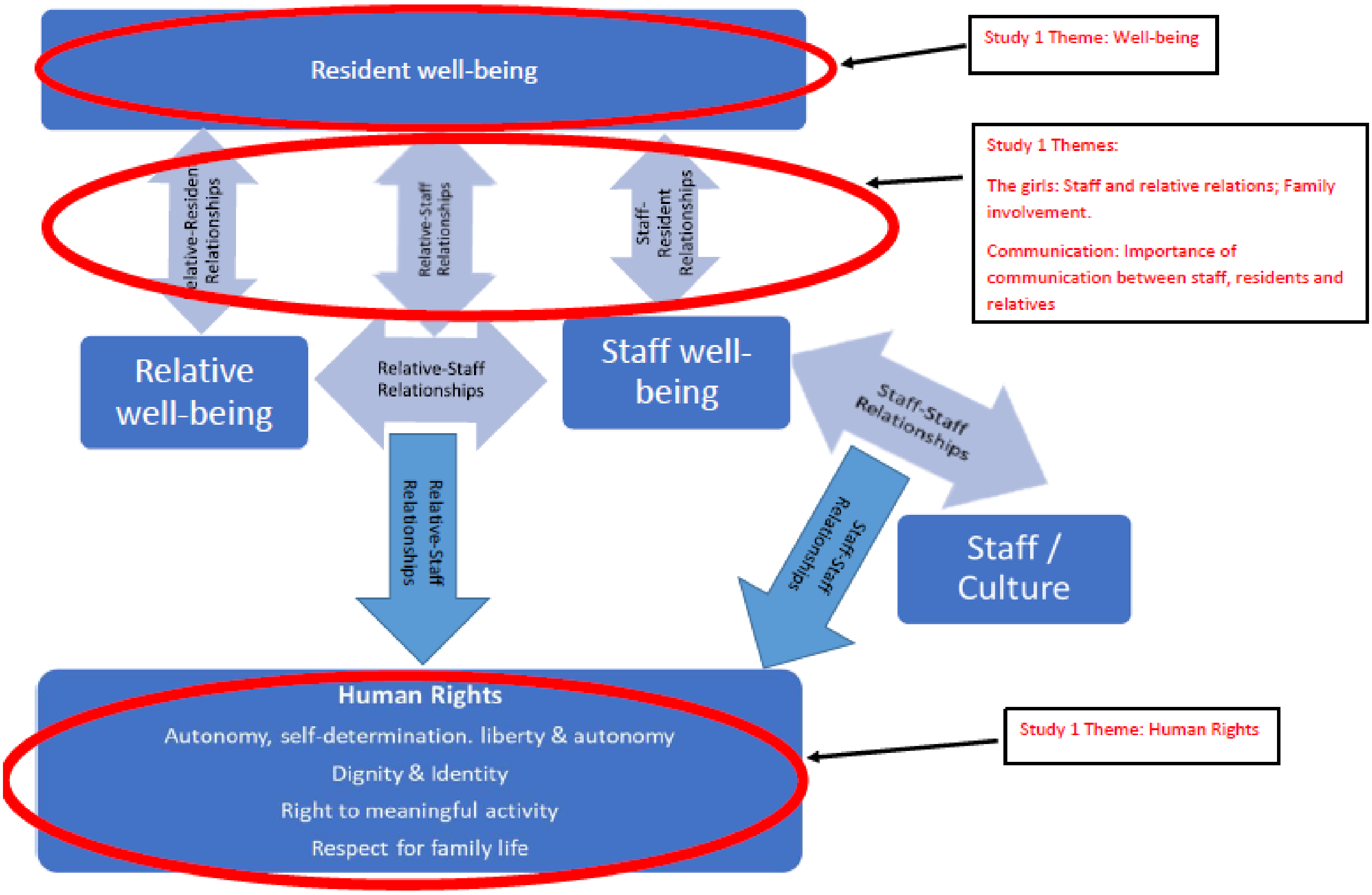
Residents’ well-being was supported by the relationship between the resident and their relatives, and by their relationship with staff. It was also influenced by the relationship between staff and relatives, in the well-established Triangle of Care (Woods et al., 2008, p.14; RCN, 2014). Relatives’ well-being was also influenced by their relationship with the resident and with the staff. Staff well-being was influenced by relationships with relatives and residents, but also by their relationship with other staff in the home, including ‘management’ reflecting the culture of the home.

Human rights encompassed discussion of difficult issues such as autonomy, individuality, dignity and liberty, best interests decision-making, and the importance of activities. The involvement of family members in the care home supported the right to respect for family life, and the relationship between staff in the home, and the implementation of the home’s culture influenced many aspects of how human rights were upheld in practice. The contrasting environments and cultures of the two homes illustrated how tensions in relationships could threaten well-being – of residents, relatives and staff – and have implications for the maintenance of human rights. For example, the time pressures experienced by Care Home 1 staff as part of the home’s culture, made upholding dignity and providing meaningful activity more challenging than in Care Home 2, which had a more relaxed, unpressured culture.

Although the themes from Study 1 do map clearly onto the understanding of the issues developed from the instrumental collective case study of Study 2, and extend the applicability of this understanding, it is clear from Figure 8.1 that a much richer picture was generated by Study 2, with its explicit inclusion of the well-being of the two other groups of stakeholders in addition to that of residents, and the identification of staff culture as an important aspect of the overall model.

In terms of the simple model presented in Chapter 1 (Figure 1.1) identifying quality of care as the link between human rights and QoL / well-being of the resident, it is clear that other factors also need to be considered as influencing the QoL and well-being of residents. Staff-resident relationships, staff culture and the culture of the home reflected in the extent of family involvement are perhaps key elements of quality of care and can indeed be seen as occupying an intermediary position between human rights and resident well-being. Standards of care were identified in the initial thematic analyses for relatives from both Care Homes 1 and 2 (see Tables 7.1 and 7.3) in relation to human rights. It is notable that, from the questionnaire data, relatives reporting greater satisfaction with the quality of the residents' care had lower levels of caregiving strain, which is also consistent with the need to consider and include the other stakeholders in understanding the relationship between human rights, quality of care and resident QoL / well-being.

Figure 8. 1 Themes from Study 1 mapped onto thematic map from Study 2



Addressing the key issues

Well-being and Quality of Life of residents

As set out in Chapters 1 and 3 of this thesis, Kitwood's influential work on person-centred care (1997) was one of the main theoretical perspectives underpinning this research. It recognised people living with dementia as unique individuals, placing 'personhood' at the centre of person-centred care delivery. Kitwood defines personhood as "a standing or a status that is bestowed on one human being, by another in the context of relationship and social being" (Kitwood 1997b, p. 8). Kitwood emphasised the importance of maintaining quality of life, dignity and integrity of individuals living with dementia. The definition of person-centred care, as stated in Chapter 1, helps us understand how collaborating with family members in care provision (Chapters 4 & 5) contributes to the QoL of PLWD, as both families and care staff commonly referred to the residents being cared for by people who knew the residents as individuals.

According to Kitwood, personhood not only lies within the individual but relies on the support and presence of others, which was evident in Chapters 4, 5 and 7. In Chapter 5, Martha and Graham were being supported as individual recipients of care, where care staff were mindful of their personalities, preferences and factors which contributed to their distress. In terms of person-centred care and personhood, care staff recognised Graham as a social character, who could eat independently, but refused meals should he not have company. Care staff made small, but very significant changes, to ensure that Graham was enabled to eat, ensuring that he was not sat alone, supporting his QoL and well-being. However, I identified in Study 2, in Care Home 1, how personhood could be reduced, where relationships were not being supported within the organisation and care staff could only meet basic care needs of residents. Such a culture also diminishes the personhood of the care staff, their sense of self-worth and identity as carers (Higgs & Gilleard, 2016; Kitwood, 1997). Where the organisation is not meeting the needs of the care staff, it is likely that the care staff will be at risk of strain and burnout, leading to negative consequences for PLWD, as care staff are not able to attend to their whole range of needs (Brooker & Kitwood, 2019).

Kitwood and Bredin (1992) identified 12 potential indicators of well-being that contribute to personhood in dementia (referred to in Chapter 1) including self-esteem, a sense of agency or control in one's life, initiating social contact and humour. In Chapter 4, I reported relatives referring to their residents' well-being to '*who s/he used to be',* relating to moments where the residents showed signs of their individual personality, humour and social interaction, and relatives associated these moments as indicators that the resident was content at the home. In Chapter 5, in Kitwood's terms (see Table 1.2), both Graham and Martha demonstrated a range of well-being indicators e.g., initiating social contact, humour, self-expression, affectional warmth, social sensitivity and the ability to express a range of emotions.

My findings in this thesis found great emphasis from relatives and care staff on well-being, referring to residents maintaining weight and gaining weight from being at the homes and also benefiting from the social environment and sharing meals with others. Brown (2016 p.263) suggests that interventions for people living with advanced dementia should begin with the fundamentals of care; eating and drinking and personal care, which are key aspects of the person's day. I also identified in Chapter 6, care staff particularly in Care Home 1, identifying these times as *"the only time we get with them*". They explained how they used this time as an opportunity to interact and engage with the residents and to promote their independence.

Drawing on the systematic review of measures of QoL applicable to people living with advanced dementia, reported in Chapter 2, the Awarecare tool and the QUALID scale were identified as potentially useful. The former did indeed prove helpful when used in Study 1, eliciting a number of the well-being indicators mentioned above for Graham and Martha. On the other hand, the contribution of the QUALID, used in Studies 1 and 2, has been less clear. Discrepancies between staff and relative ratings seen in both studies indicate that scores may reflect factors related to the raters' perspective as well as the residents' life experience. These rater-driven differences did not appear to reflect the raters' strain or well-being, but it could be speculated that they reflect the nature and duration of the contact with the resident, their prior knowledge of the person and their expectations for life with advanced dementia. The lack of difference in QoL ratings between the two homes in Study 2 did not fit well with relatives' ratings of satisfaction with care, or of staff reports of the culture and atmosphere in the two homes. The findings from the (limited) practical application of the QUALID in this study leads to more questions about its usefulness in describing QoL in advanced dementia and does not provide any support for its routine use in practice.

Well-being of relatives and staff

The results from the studies in this thesis provide support for the benefits of the triangle of care. The triangle of care in dementia care refers to the network of relationships between individuals living with dementia, paid caregivers and families, and particularly highlights the crucial role played by families even when the person with dementia is receiving 24-hour care in a hospital or care home. Staff in such settings need to develop good relationships with family members to ensure better outcomes for people with dementia (RCN, 2014; Woods et al., 2008 p.14). Within the context of positive relationships, the needs of the paid caregivers and families are met, as well as those of the residents, with paid caregivers and families learning from each other during the process (RCN, 2014; Woods et al., 2008). In this study, the advantages of the triangle of care were evident in that the collaboration seen in Chapter 4 contributed to the QoL of residents and had positive implications for both care staff and family members. In Chapter 4 care staff acknowledged their caring role involves both residents and their family members. Equally, family members also noted that they were not only visiting their relatives, but they also visited to support the care staff. There was a similar picture in Care Home 2 in Chapter 7, where relatives were part of the ‘family’ of the home. In contrast, there were tensions in relationships between relatives and staff in Care Home 1, despite efforts to see each other’s perspectives. It is plausible that these tensions were amongst factors leading to greater strain in relatives and lower staff well-being in Care Home 1 compared with Care Home 2.

The daily involvement of many relatives in Study 1 is not, of course, available to all residents, and during COVID-19 was possible in only exceptional circumstances (see section on COVID-19 below). In cases where individuals do not have regular involvement of family members, they will be completely dependent on care staff as advocates. The quote from a Study 1 relative which precedes Chapter 6 sums up the difficulty well: ‘*But I feel for people who don’t have visitors here, there’s nobody watching over them you know?’*

In Study 2, relatives - mainly adult children - who did not visit daily were included. Although visiting less frequently was not directly related to increased strain in relatives, the results suggest that visiting more frequently, in line with previous findings (Grabowski & Mitchell, 2009), provides some benefits for relatives in relation to feeling more involved in decision making and experiencing greater sensitivity from staff to their needs. Thus, more frequent visiting possibly provides an opportunity to build relationships with the care staff and collaborate in terms of care planning and decision making. Perhaps, in Study 2, specifically where families’ involvement in the care home was not frequent, care staff had identified themselves as advocates of the resident, and therefore did not routinely consider updating families around changes in care planning.

Although recruitment in this project of substantial numbers of relatives living at a distance, and so visiting infrequently, was not possible it is important to consider the involvement of family members who live a distance from the care home and how to maintain their involvement. Care homes should to the fullest extent possible, involve and inform family members in care planning and procedures. This could be achieved by designating staff members as primary contacts for families, to facilitate their regular communications by methods, such as telephone, email or video calling. This has been necessary for all relatives during the pandemic and should become standard practice for families at a distance.

Human rights

The second theoretical underpinning for this research (see Chapter 3) was the FREIDA approach to human rights. This approach provides a human rights view of QoL (as defined in Chapter 1, Curtice & Exworthy, 2010; Butchard & Kinderman, 2017; see Table 1.3). As I have discovered in these studies, there is a lack of knowledge and understanding of human rights in dementia care. In Chapter 5, I found 'identity' a highly relevant factor, which resonates with 'personhood'. In Chapters 4, 5 and 7, relatives and care staff referred to upholding the identity of the individual. In terms of the principle of 'fairness', I identified in Chapter 5 and Chapter 7, in both care homes belonging to the same organisation, the lack of Welsh language care provision for residents as a barrier in meeting residents' individual needs (not unique to this organization, see Martin et al., 2018).

In relation to respect, dignity and autonomy, a clear threat, perceived by relatives and staff in Chapters 4 and 7, was the pressure of time and staff resource. In Chapter 4, a relative was quoted as saying '*it's not giving the rest of the residents enough attention'* when staff resources were taken up assisting a disruptive resident. Similarly in Chapter 7, relatives discussed where the residents' dignity had been compromised, and care staff reflected on residents' autonomy, with pressure of time leading to staff, for example, dressing the person rather than assisting them to dress.

Providing person centred care in care home settings whilst balancing the needs of other residents is a constant and challenging process (Evans et al., 2018; Kadri et al., 2018). To balance the needs of individual residents requires continual assessment which often begins prior to the admission into the care home, with care home managers visiting individuals to assess their needs against the care home's ability to meet these needs, given the needs of existing residents in the home.

Findings from this project have highlighted contradictory themes in the discourse and practice in relation to balancing the needs of individual residents. On one hand, care staff were striving to provide care to meet the individual's preferences. On the other hand, the care staff were meeting the deadlines given, in order to complete set daily tasks. Research has shown where time demands are placed on care home staff, they are having to prioritise tasks to be completed against the individual needs and preferences of the residents (Evans et al., 2018; Kadri et al., 2018; Ward et al., 2008). A further challenge faced by care home staff is the ratio of staff-to-residents. As well as the lack of time, there is the risk that meeting the needs of one resident would be at the expense of other residents. Therefore, meeting an individual's needs could come at a cost to other residents.

Juggling the needs of the residents against workload and staffing levels seems to be part of the culture and everyday occurrence in care homes (Evans et al., 2018; Kitwood, 1997; Kadri et al., 2018). Individuals living with advanced dementia in care homes have increasingly high levels of needs for care and support. This leads to increased staff training needs and a need for higher staffing levels in already over-stretched and underfunded care homes. However, in Study 2, one care home appeared much less driven by time pressures than the other, suggesting there may be strategies for achieving a balance. More research in this area is required to support balancing the needs of individual and person-centred approaches in a communal setting and understanding the role of staff-resident ratios in this (Evans et al., 2018).

Despite the lack of open discussion of human rights, it is evident that care staff and relatives can and do apply the FREIDA principles to the care of people living with advanced dementia. However, it is not enough for these principles and approaches to exist, an understanding of how these principles can underpin and transform care practices is required.

Care home design

Although not a specific identified issue, the research has provided some insights regarding the care home environment and its impact on well-being of residents, relatives and staff. In Study 1 the research took place across 2 homes, both designed specifically to provide dementia care, operated by an independent care home group. Both homes had been nominated for awards in relation their design, and one home had been ‘Care Home of the Year’ in a national competition. Both homes comprise of individual households for people living with dementia. Each household within both homes was independent from one another and specific staff were allocated to each of the households, providing continuity for the residents and their relatives. Every household provided a main living area and a quieter living area, kitchen, bathrooms and residents’ individual bedrooms.

Each household was home to an individual community, made up of residents, families and care staff. My findings would suggest the layout of the homes in Study 1 as households created a supportive environment for residents, relatives and care staff. The nature of the households saw families building rapport with one another, where relatives would also spend time with and were inclusive of residents who did not have a visitor. Further, the relationship between the families and care staff extended beyond care of the resident. Families were mindful of the care staff's well-being and vice versa; families would often bring in food for the care staff and offer to assist them with personal tasks, such as sewing or fixing items of personal clothing. Also, staff members would support the family members with setting up new electronic items and registering for social media platforms, where they could connect and keep in touch with other family members.

However, the care home organisation's thinking behind the households was that each household provides care at a different stage of the dementia journey. On review, the care management team may decide that an individual may be best placed in a different household based on progression and care needs. Due to the individual communities the households had formed, naturally relatives of residents were sometimes concerned at the decision to move a resident to a different household. The relatives expressed their concern around continuity of care and the impact of the different environment on the resident's well-being. Further, the relatives highlighted the negative impact on themselves, as they would no longer benefit from their current community. Despite this, there were instances where the relatives and the care home team decided by mutual agreement, a resident may benefit from an environment provided on a different household and residents and families could spend periods of time on the proposed household, prior to making a decision to move.

In Study 2, I worked with the same organisation providing the sites for Study 1 in their transitioning home 'Care Home 1'. The home had not been designed to provide dementia care and major changes were being implemented to the design of the home during the fieldwork. At the time of data collection, the home was split into two sides, with one side of the home providing general nursing care and one side providing dementia care. The section of the home providing dementia care, was soon to become their specialised dementia care unit, providing a layout of households featured in their homes in Study 1. During the time of data collection, the designated side of the home for dementia care, was a large space, with various living areas and quieter rooms and linking corridors.

It was evident during this data collection period that residents, relatives and care staff were not as close knit as the participants in Study 1, with relatives in Study 1 often arriving for the day and were no strangers to the washing up! However, the families visiting their relatives in Care Home 1 were 'visitors' who were explicit about not feeling involved by the home.

Despite the relatives' empathy for care staff and the care staff wanting to provide person centred care of their relatives, they missed the opportunity to discuss and plan together. Due to the period of transition the living spaces used for residents would change daily, also making it difficult for family members to form relationships with each other and making more tenuous their relations with care staff, who worked across all areas throughout the day. Further, care staff in Care Home 1 were having to contend with many external factors. The care staff were managing several large areas throughout the day, and sometimes having to relocate to different areas of the home with residents, based on the construction work that was planned or required.

In Care Home 1, there were tensions between family members and care staff regarding the relocation of residents to different living areas, with family members expressing their concerns and dissatisfaction with a number of the temporary living areas chosen. Further, the care staff in Care Home 1 had worked under a temporary management for a number of years, with the home facing the prospect of closure. Despite the home being saved from closure by the in-coming organisation, this did not come without challenges and complexities, with several families having purposefully chosen a home, independent from that organisation. Care staff were continuously on the front line of the dissatisfaction of the relatives in the home, whilst having to digest major changes to their employment and work environment.

In study 2, Care Home 2 provided the opportunity for an independent data collection site and in contrast to Care Home 1, there were no designated spaces created for PLWD, and the home did not have the small group living size usually recommended in dementia design guidelines. Despite all of the residents in this home sharing one large communal space, this did not appear to detract from their QoL. The one living space promoted a sense of community, with residents vocal about where they wanted to sit and with whom, and they assisted each other with different tasks and activities. Also, the one large space did not only bring residents together, but the care staff and the residents' relatives. The set-up of this home and the living area created a space for bringing everybody together, which was also an advantage to the care staff, who felt supported by the manager, whose office was also located in the living area. Also, the majority of the arranged daily activities took place in the communal living area, with relatives attending specially to take part! Relatives of this care home referred to the Care Home as their social life and their source of support, which they were lacking prior their relative moving into the Care Home. One relative spoke about how the support he had received as an individual had changed his life, and the home had provided him with his own ‘name badge’, referring to him as ‘*one of the team’*. The setting for Care Home 2 had clear positive elements of both care homes I studied in Study 1, with residents, relatives and care staff all benefitting from the social environment, perhaps suggesting the physical environment does not have to be a barrier to creating a sense of community.

Although opportunities for research on interventions in care home settings are increasing, the methods relating to people living with advanced dementia are lacking, with multi-sensory interventions such as Namaste Care a major exception (Bunn et al., 2018). In my study, all three homes belonging to the care organisation had a Snoezelen room, equipped for multi-sensory stimulation. However, they were not commonly used, or not used for the intended purpose, in line with previous findings (Jakob & Collier, 2017).

Implications: theory and practice

Inclusion of people with advanced dementia

During this study I have shown the importance of including people living with advanced dementia in research and how their daily lived experiences in care homes can be observed to inform future practices. I have also identified how people living with advanced dementia with limited communication ability can partake in research. As I presented two different individuals Graham and Martha, in Chapter 5, by employing the AwareCare tool, I was able to capture something of their actual lived experiences at the care homes, as well as key elements that were of importance to their QoL and well-being. This study presented two care home residents as individuals living with the same illness but expressing a range of different behaviours and responses. Families and staff described a number of means they used to assist communication with people with advanced dementia, especially non-verbal indicators of the type that form the basis of the AwareCare tool. I also found that ‘Talking Mats’ (Murphy & Oliver, 2013) could be a useful aid to communication, that was not being used in the homes studied.

Recognising the personhood of staff

The expectations set by the care home management create the environment experienced by residents living in the homes. Therefore, their understanding of how the expectations they set and the procedures they operate translate into care practice is crucial. The support provided by the management, alongside the resources available, will ultimately affect how care staff are able to deliver person-centred care. There is a close connection between person-centred care of the resident and the personhood of the care staff, and the care that they are able to provide and this can impact their identity as a caregiver. Care providers must move beyond the quality of life and personhood of the residents and must consider the personhood and QoL of their staff. As I have identified in Chapters 6 & 7, the well-being and strain of the care staff, affects the residents which in turn impacts the relatives. I found where care staff were not able to provide the care they wish to give as a carer, this was at a great personal cost. However, they were conflicted by expectations of their management and families, a situation they found themselves in daily and difficult to manage. However, in Care Home 2 in Chapter 7, where management were also involved in the daily practices and procedures, care staff identified themselves as part of a wider team and reported higher levels of well-being than those reported by Care Home 1 staff. Further, I saw positive interactions between residents, relatives and care staff, where the conditions created allowed for key stakeholders, residents, care staff and relatives to flourish. However, it is important to note that the findings indicate that quality of care does not necessarily equate to quality of life, and in order to achieve this, care home organisations must allow for opportunities for residents, outside of their basic care routines.

Human rights

Dementia as a human rights issue has been lacking in priority in the past. Despite a growing focus on human rights in social care over the years, human rights within dementia were not routinely considered (Dementia Alliance International, 2016; Kelly & Innes, 2013). However, in recent years there has been growing recognition of the rights of people living with dementia, as they have been highlighted by people living with dementia, family carers and Alzheimer's Societies, who have campaigned for a human rights approach (Alzheimer Europe, 2017; Dementia Alliance International, 2016).

Dementia working groups, consisting of people living with dementia, family carers and supporters have been campaigning for significant change, working in collaboration and alongside organisations and governments to reduce stigma, discrimination, and highlight access to civil society as a human right. However, my findings from Study 1 indicate a lack of discussion around human rights. From a relatives and staff perspective, human rights were not widely discussed within the care homes, coupled with confusion and negative perception surrounding human rights in care homes, in line with findings from DEEP (2016), that suggested a negative perception of human rights coupled with a lack of understanding exists, in terms of human rights and dementia.

Familiarity with this topic could support the promotion of human rights and help to reduce resistant views. It has been reported that, where people lack understanding and knowledge about a topic, their resistance towards the topic is higher (Equality and Human Rights Commission, 2018). Care home management may assume that knowledge surrounding human rights and how they apply is apparent, but evidence from the current research project has indicated that understanding of human rights, how to implement them within care home environments, and how they are actioned need to be addressed. Within the context of dementia, safeguarding and protective practices are common themes, as opposed to those of enabling and empowerment (Cahill, 2018). Discussions around human rights in care have commonly focused on severe cases of abuse and ‘Do Not Resuscitate’ policies, neglecting the everyday aspects, such as, the right to exercise choice and control over matters crucial for independence, autonomy and well-being (Cahill, 2018). Whilst rights are becoming increasingly familiar within our society, further investment is required to educate on how to promote and maintain human rights for people living with advanced dementia as recipients of care.

Human rights and dementia as a disability

There is increasing attention to framing dementia as a disability and the Convention on the Rights of Persons with Disabilities (CRPD) allows PLWD to be seen as part of mainstream society (Cahill, 2018). A ‘rights-based approach’ to disability has become increasingly known within health and social care, as a best practice approach, bringing the individual’s needs to the forefront of the care they receive. The CRPD has been recognised as creating a paradigm shift with regards to human rights and people living with disabilities. The CRPD is becoming increasingly known amongst dementia rights advocates and supporting organisations. There are many advantages of recasting dementia as a human rights issue and under ‘disability rights’ (Cahill, 2018) as the CRPD commits to the rights of people living with disabilities and the fundamental equality of people with disabilities to those without disabilities and asserts that disability is not a legitimate cause to reduce or dismiss them (Dementia Alliance International, 2016).

For PLWD the CRPD has enabled them to challenge decisions and enabled them to access services, and access their rights, such as remaining in work (All-Party Parliamentary Group on Dementia, 2019). The Dementia Alliance International has drawn on the CRPD to question circumstances PLWD face in care home settings (Dementia Alliance International 2016), to draw attention to the confinement, referring to locked doors, constituting deprivation of liberty. Attention has been drawn to instances where residents were unable to leave or move around freely as they do not have access to the means to unlock the door, and it has been widely understood that, in some instances locking doors occurs where there is no legal order in place (Smith & Sullivan, 2012).

Human Needs and Human Rights

Whilst it is becoming increasingly recognised that dementia is in fact a disability, the discourse on dementia has largely centred on personhood and human needs (Kitwood, 1997b), not human rights (Mental Health Foundation, 2015). Therefore, a human-rights based approach has rarely been applied to challenge practices and procedures, and discrimination.

In framing dementia as a human rights issue, it is important to consider human needs. Needs are subjective and relative (Bradshaw, 1994), 'statements of values, of ideologies, rather than statements of fact' (Ife, 2012 p.126). In contrast, rights are absolute, and bound by a legal framework, requiring legal intervention. Recognising needs within a human rights approach, translates 'needs' from a vague notion to be achieved, to firm entitlements (Cahill, 2018). Perhaps another difficulty in framing dementia as a human rights issue, is that 'needs' can and have been ranked and prioritized, and rights are unknown territory, often linked with negative outcomes in care (Cahill, 2018). As noted by Ife (2012), Maslow's hierarchy of needs pyramid (1970), demonstrates how needs can be ranked from basic needs to higher level needs including belongingness, love self-esteem, and self-actualisation.

Human rights and Palliative/End of life care

Currently, there is no formal 'right' to access palliative care services, despite palliative care services being developed, people living longer and transitioning into later stages of dementia. Although dementia is a life limiting condition, there is little consideration of dementia as a terminal illness which requires end of life care. A greater focus has been given to the earlier stages of dementia, where individuals are supported to 'live well' with dementia, with little regard for the individual's wishes regarding their death and 'dying well'. However, a palliative care approach is appropriate to introduce at any stage of the illness (Van der Steen et al., 2014) which supports the individuals' autonomy, providing opportunity to make decisions in accordance with their wishes, even if capacity is lost (Dening et al., 2012). Care strategies for PLWD should include end of life content and planning; a palliative care approach improves QoL for the individuals living with dementia and their families (Nakanishi et al., 2015). Advanced care planning for end of life allows individuals to prepare and is not dependent on the timely recognition of dying, to begin the discussion around the individuals' wishes and goals of care (Nakanishi et al., 2015).

Human rights and care planning in a crisis

Individuals living with dementia are at an increasing risk of requiring urgent healthcare support and emergency care planning (Dooley et al., 2020; Goodman et al., 2015). Whilst avoidance of emergency care is important, there is little research that aims to explore what factors affect urgent care situations for individuals living with dementia or their experience of emergency care (Dooley et al., 2020). Advanced care planning is frequently recognised as a crucial factor in advanced dementia care (Dooly et al., 2020; Diehl-Schmid et al., 2018; Eisenmann et al., 2020; Ryan et al., 2017). However, as with the nature of the illness, it is difficult to predict exactly how the individual's dementia journey will evolve.

Care home placements for PLWD often occur in emergencies, or at the very least at short notice. This can make the move more difficult as the added pressure of time constraints is a major factor (Goodman et al., 2015). Where families and individuals are short on time, this could leave less time to find a suitable placement for the individual's needs. Discussions around goals of care would ideally take place within the context of a longitudinal clinical relationship. However, amid the complexities of the illness and navigating services, these discussions often do not occur (Dooley et al., 2020; LeBlank & Tulsky, 2020). When discussions occur in emergency situations, the goals of care planning may need to be initiated by professionals who do not know the PLWD, such as the care home manager on emergency admission. Without the context and trust of a long-term relationship, goals of care discussions can be particularly complex and distressing. In situations where an individual does not have family, the situation becomes even more challenging (LeBlank & Tulksy, 2020). Indeed, the crisis may have been precipitated by the illness or death of a relative. The personhood and identity of the person with dementia is at risk where the person is not 'known' by those providing care.

However, prior to care home admission the individual will be known to community or hospital services, and a personal profile for the individual should exist (implicitly at least) amongst services, such as the local GP practice, district nurses and Memory Assessment

Services. Where an individual is moving into a care home in an emergency situation, human rights considerations would suggest that the care home liaise with local healthcare and outpatient services to build a personal profile for the person living with advanced dementia (LeBlank & Tulsky, 2020). Although systems should exist to support this process, such as shared documentation, and in some cases advance care plans, documentation alone will not be enough to guide care requirements (LeBlank & Tulsky, 2020). This process will require a number of people to become involved to provide information about the individual, which will help them interpret how to promote well-being for the individual, alert them to deterioration and complement information that can be provided by known family members. Where the person is admitted following a crisis hospital admission, there is a particular responsibility on the hospital to ensure a good handover of as much information as possible, and for any family or close friends to be fully involved.

The right to activity and occupation

Within the Human Rights Act (HRA), there is no specific mention of a right to ‘activity’ per se. However, under article 15 of the HRA, everyone has the freedom to choose occupation and have the right to engage in work and everyone has the right to pursue a freely chosen occupation. Of course, in our day-to-day lives, we would refer to occupation as our freedom to work and participation in work. But where and how does this right apply to people living with advanced dementia? If everyone has the freedom to pursue a chosen occupation, how do people living with advanced dementia exercise this as a right?

The term occupation is used to describe a job or profession in everyday language. However, within the field of Occupational Therapy, it is used to describe a set of activities which people use to fill their time and give life meaning, and centres around roles or activities of daily living, work and productive activities, for pleasure, for survival, for necessity, and for personal gain. It is the individualized, unique combination of activities that comprises an individual's occupations (Pierce, 2001).

What encompasses activity is diverse, there is no consensus on what exactly makes up ‘meaningful activity’ (Marshall & Hutchinson, 2001; Phinney, 2006). Consisting of household tasks, social involvement, work-related, recreation, activities become meaningful through the sense of purpose, autonomy and achievement associated with participation, despite level of cognitive impairment (Mansbach et al., 2017).

The stress on the significance of occupation has been well documented. Research has shown many advantages linked with activity and ageing, including numerous health benefits, such as improved cardiovascular health, decreased levels of diabetes and reduced falls (Mansbach et al., 2017), improved well-being and QoL (Smith et al., 2018), reduced cognitive decline, as well as being valued by older people (Stenner et al., 2011). Previous research with people living with (mild-moderate) dementia, found participation in activity associated with feelings of belonging and identity, Genoe & Dupuis, 2012; Harmer & Orrell, 2008; Lawton, 1994; Phinney, 2006; Tierney, 2020) and fulfilment through choice, control and belonging (Mansbach et al., 2017).

However, despite activities bringing many advantages, due to the progressive nature of the illness, PLWD at a particular stage may be unable to initiate activities independently and therefore, it becomes the work of those around them to support and facilitate this (Mansbach et al., 2017; Schreiner et al., 2005). For residents with dementia in care home placements, cognitive limitations and reductions in autonomy, create dependencies on care staff to provide activities. As a result, engagement in meaningful activity becomes a reflection of the quality of care provided by the care home.

The right to family life

Care homes can provide an environment where families can maintain their roles and relationships as family members and remain as partners in care. Many individuals living in care homes will rely on family and friends to provide social and emotional support (Downs, 2013; Kelly, 2010; Lee et al., 2017; Hado & Feinberg, 2020). Additionally, families are also advocates of the residents' care and assist with surrogate decision making, where the individual has lost capacity. As families are equipped with the knowledge of the resident as an individual, they are also able to understand and articulate and support the needs and wishes of the individual (Reinhard et al., 2019).

The promotion of family life in care homes adds to the sense of community in the care homes, which also provides additional support to the care staff, which serves as an advantage to the care home as a whole (Brooker & Kitwood, 2019; Hado & Feinberg 2020). The current pandemic has also highlighted how care homes are also reliant on the support of families and friends as they serve as important partners in the residents' care and the devastating impact the ban on visiting has had on residents, relatives, and care staff (Hado & Feinberg, 2020).

Human rights and identity

In Chapter 5, a strong sense of 'identity' was identified for both Martha and Graham, and the promotion of their personhood through the responses of the care staff to both residents, as individuals. Although life story work directly with people with advanced dementia might be difficult, encouragement for people with milder levels of dementia to work on life story books (conventional or digital) would ensure an identity-upholding resource was available for family carers and professional caregivers if the person's impairment increased. In the absence of this, relatives are able to produce useful resources, so that the person is known as an individual (Subramaniam et al., 2014). In Study 1, both care homes had 'memory boxes' outside each residents' room, to encourage families to provide photos and memorabilia that expressed something of the identity of the person.

Building human rights into care practice

This study has shown there is an even greater need for an open discussion regarding human rights in care homes, to promote a positive cultural shift. As human rights are often coupled with legal frameworks and the 'dark' side of health and social care, perhaps their potential as a building block in providing quality of life and quality of care is not considered. As identified in Study 2, key aspects of human rights for relatives were in aspects such as family life, participation and engagement, dignity and identity, and enabling the residents. Families were keen to see their residents being able to participate and engage with others, outside of their routine care procedures, access nearby gardens and remain a part of the community, visiting their local church or their family home. Both relatives and staff also referred to residents' rights being taken away, where the care practices reduced their opportunity for independence and involvement, reducing their well-being. However, providing quality care does not necessarily mean that an individual's rights are being promoted, they may receive gold standard care, but not have the opportunity to engage.

Based on my findings I would recommend small but effective steps, including open discussions around principles that are important to residents, care staff and family members and how they can be achieved in care procedures. Rights need to be understood at a level where people can apply them to current situations, to ensure that they are promoted, rather than simply avoiding abuse. The tensions that arise when care needs to be provided and the person makes clear they do not want to receive it (e.g. in relation to incontinence) need to be openly discussed, and alternative strategies identified. The aim is to act in the best interests of the person with advanced dementia, but to help them to feel a sense of autonomy and control in the difficult circumstances they are in.

Complex family relationships

This research has highlighted the continued role of family members as caregivers of people living with advanced dementia in care homes. The study has offered further indications of the benefits of family involvement in care homes, 'sharing the care' (Brooker & Kitwood, 2019). As identified in Chapters 4 & 5, the support provided by families extends beyond care of their own relative, but to those with absent families, care staff and the home as a whole community. Huge benefits are gained in an open and welcoming home, the home has added to its staffing at no additional cost, and families are enabled to provide the care they want to give, in collaboration with the home (Brooker & Kitwood, 2019). These findings have shown the benefits to residents, as well as acknowledging the relationships established beyond the care staff and residents, that of the care home and families.

Although the importance of family involvement and of the relationship between the resident and his/her relatives has emerged strongly from both empirical studies reported in this thesis, it would be naive to overlook the potential for such involvement and these relationships to have a negative aspect. In Care Home 1, for example, relatives were reporting levels of strain considerably higher than those reported by family caregivers providing day-to-day care for a person with dementia at home.

Relationships may also have their negative aspects. Woods et al. (2008) point out that relatives may be seen by the care home as not acting in the best interests of the resident, and this may lead to difficulties in the staff-relative relationship. Within families there may be disagreements and conflicts, which will then also have an effect on the triangle of care. There may be long-standing difficulties in the relationship between the person with dementia and their relative, or the onset and development of the dementia may have upset the balance of family dynamics, causing conflict and perhaps aggression or abuse.

A previous study identified 'reluctant helping relationships' and 'task-centred relationships' between families and individuals living with dementia, which diminished personhood. Within this kind of relationship, motivation behind supporting their relatives was driven by a sense of duty and obligation, rather than love and affection (Smebye & Kirkeyold, 2013). Where previous relationships were strained, family members were embarrassed by behaviour and attributed this to the individual's ill intentions rather than to the disease (Smebye &

Kirkeyold, 2013). They further identified where a caring relationship had lasted many years, family carers' personal needs were left unmet, leaving them tired, burnt out and frustrated.

At the extreme, family relationships may become abusive, of course. From a systematic review, McCausland et al. (2016) estimate that the prevalence of domestic abuse (physical and psychological) involving people with dementia is between 11% and 19% over the previous year. They report that people with dementia are at greater risk of experiencing domestic abuse than those older people without dementia, and that the risk is greater where there was a history of abuse before the onset of the dementia. It is reasonable to expect that a proportion of those so affected will be admitted to care homes, and so there are likely to be at least some residents who have experienced such abuse at the hands of their relatives prior to admission. Accordingly, there must be some degree of risk that this abuse may continue following admission, although this risk may be reduced to the extent that the abuse arose in the context of negative interactions during hands-on caregiving and related high levels of stress and burden.

However, the literature on elder abuse in care homes focuses primarily on abuse of residents by staff. For example, from a large UK study, Cooper et al. (2018) indicate that as many as half of care home staff reported either witnessing or themselves carrying out actions that could constitute neglect or abuse in the previous three months. These actions were reported to occur at least sometimes in all but one of the 92 care homes included in the study and were more common in homes where levels of staff burnout were high. Neglect and avoidance were much more commonly reported than physical or verbal abuse. Yon et al. (2019) report, from a systematic review of the international literature, that almost two-thirds (64.2%) of staff admitted elder abuse in the preceding twelve months. They acknowledge that their review was not able to include forms of abuse other than staff-resident, with no information available regarding visitor-resident abuse, for example.

One of the few studies to address other forms of abuse in care homes comes from Norway, where Myrhe et al. (2020) sought the views of 28 nursing home leaders, through a series of six focus groups. They identified three categories of abuse and neglect. Firstly, resident to resident, which was seen as a normal and expected aspect of life in the care home. Secondly, abuse from staff directly providing care, which was seen as a breakdown of trust between managers and employees, and very difficult to discuss. Thirdly, abuse of residents by relatives visiting the home. This was seen as difficult, but should be kept private, between residents and relatives. It was seen as often arising from past family conflicts or being related to the relative's drug abuse or mental health problems. Financial abuse was described as occurring frequently, including misappropriating the resident's financial resources, or not allowing the purchase of items the home considered essential, but which were not included in the care home fees. Some decision-making by relatives on behalf of the resident was also highlighted as an issue, with the home leaders considering that sometimes the resident's interests and needs were over-ridden. Myrhe et al. (2020) conclude that the management of abuse and neglect in these nursing homes gave rise to concerns regarding the safety of residents, with leaders not having the necessary knowledge or procedures in place.

Whilst in England and Wales the Mental Capacity Act and safeguarding policies and procedures should prevent relative-resident abuse being seen as a private matter, within the family, care homes do need to strike a balance between being suspicious of all relatives and their motives and missing what is happening behind a closed door or through the relative's management of the resident's financial affairs. Good, open, supportive communication between the home and relatives is recommended by Woods et al. (2008) in their guidelines for care homes on family involvement. The involvement of advocates may be needed where there are concerns regarding best interest decisions, and regular case reviews with professional social workers and family involvement should be the cornerstone of care planning. Direct care staff need to be supported in developing good communication with residents and relatives. They will often be in the best position to pick up any signs that something is wrong, for example, if the resident becomes anxious when approached by a particular visitor, or if the visitor appears to be under the influence of drugs or alcohol or becoming very distressed. Continuity of care and a stable staff team will assist the development of open, trusting relationships. Direct care staff need to know that their concerns will be taken seriously by managers and senior staff and be involved regularly in discussions regarding the well-being and human rights of the residents in their care. An open, non-hierarchical management structure will provide staff with more confidence to share their observations with those who will need to assess and take appropriate action where required, including the involvement of Social Services departments as necessary.

The impact of COVID-19 and its consequences

The impact on residents, relatives and staff

The pandemic has had a huge impact on care homes. People with dementia have been at disproportionate risk of dying from COVID. Relatives have been subject to draconian visiting restriction. The bizarre spectacle of 'window visits' has become commonplace. Care staff have faced huge challenges to provide care, in the face of staff shortages from staff absence due to sickness and self-isolation adding to pre-existing shortages.

'John's Campaign' and several dementia-supporting organisations have campaigned tirelessly to highlight the devastating effects of the enforced separation of families, from their loved ones living in care home placement (Dementia UK, 2020). During the pandemic, there has been a devastating impact on care homes, a very much hidden crisis faced by those living in care homes, their family members and care staff (Dementia UK, 2020; Alzheimer's Society, 2020).

Despite some issues being highlighted regarding older people on important subjects such as loneliness, isolation, and investments to mitigate such circumstances, care home residents are equally facing extreme loneliness and isolation, being separated from family and friends, and in some cases, having little or no understanding as to why they are no longer receiving visits from their loved ones (who in some cases may have been previously visiting daily). As my findings have indicated, families and friends provide residents with social interaction and assist care staff with individual knowledge about the residents and in some instances continue their roles as carers working alongside care staff, as well as monitoring and advocating for their needs. In an open letter to the Secretary of State, John's Campaign called on the government to reconsider their decision regarding restricting visiting by families of residents living with dementia in care homes, which continued even at times when outside care homes restrictions had eased. They called on the Secretary of State to recognise family members as essential 'key workers' (Dementia UK, 2020).

During the pandemic, care staff have been under dual strain of fear of infection and the residents decline (Wang et al., 2020; Alzheimer's Society 2020), and are witness to the severe impact of enforced separation and social isolation on PLWD (Wang et al., 2020; Gordon et al., 2020). In the current situation, care staff are now facing additional pressure to facilitate 'visiting' for families, as best they can, through means of telephone calls, virtual calls and ‘window’ visits (Gordon et al., 2020). During this research project, I had already identified care staff feeling the strain of completing their expected daily tasks, even where family members had been able to support them, with practical support and knowledge. However, during the pandemic families have now become completely dependent on care staff to maintain the QoL and human rights of their relatives, facilitate connection with their loved ones, and provide in-person and physical contact (Wang et al., 2020).

As I have highlighted in my studies, the collaboration between families and care staff was essential to maintaining the QoL and human rights of PLWD. Additionally, I identified the implications of relationships and the importance of building relationships between key stakeholders: residents, relatives and staff members. In the pandemic, those relationships are even more fundamental. Furthermore, the rapport between families and care staff becomes crucial, when families become fully reliant on the staff, to deliver all aspects of care provision, and as primary advocates of their relatives.

For people living with dementia specifically, there has been a sharp rise in the number of deaths in care home placement, higher than any other group. Figures published by the Office for National Statistics have shown the devastating impact of Covid-19 in care homes for people living with dementia and their families. Figures indicate half of all deaths in care homes from Covid-19, have been people living with dementia. Aside from coronavirus, ‘unexplained excess’ deaths for people living with dementia, were 83% higher in England in April and 54% higher in Wales, with nearly 10,000 deaths in total (Alzheimer’s Society, 2020). Alongside the devastating figures, people living with dementia are deteriorating, due to the detrimental effects of the imposed isolation. Families are anxious that when they are permitted to visit, their relatives will no longer recognise them (Alzheimer’s Society 2020).

Communication with families

During the pandemic, there have been many examples of care staff having kept families in contact with their loved ones through various video calling methods, a facility that they may have used very rarely or not at all in the past. This ‘new’ and modern way of keeping in touch may now become part of the ‘new normal’ in keeping families at a distance in touch with their relatives, a method that will now be considered more routinely in the future. Keeping in regular contact may also bring some balance to potentially strained relationships between the care homes and family members, supporting open discussions regarding care and helping families feel more involved in the care processes (Hado and Feinberg, 2020; Lynn 2020).

Consideration should be given about how best to meet the needs of all three groups and time should be allocated to care staff to support residents and families in keeping in contact. This needs to be seen as an integral part of the care home's work, not an optional extra. Keeping regular communications may support relatives from a distance provide effective support and information regarding their relative, possibly supporting distant families not to remain distant (Thompsell & Lovestone, 2002; Hado and Feinberg, 2020). Even where physical visits are not possible this should not inhibit relationships and connections between residents and their family members, which are fundamental to well-being.

COVID-19 and human rights

The COVID-19 pandemic brought the challenge of balancing the needs of multiple residents living in close proximity to the fore. By virtue of living with others in a care home, the person faced more restrictions than if he/she lived in the community. During the pandemic, it is widely agreed, the needs of people living with advanced dementia in care homes were neglected. A report by The Joint Committee on Human Rights (2021) highlighted the inconsistencies in the guidance when considering the needs of care home residents and their families during the pandemic and questioned whether the Care Quality Commission has been effective in defending their rights.

The pandemic highlighted the flaws in the care home model, where the cost of protection from the virus was to remove human rights of the residents (Alzheimer Scotland, 2022; Joint Committee on Human Rights, 2021). Challenges were faced by care home providers as they sought to balance the rights of residents and families to be together, with the need to protect the residents from the virus (Joint Committee on Human Rights, 2021). However, two years of strict limitations on visits in care homes enforced by care homes have been found to infringe human rights—in particular the right to life, the right to liberty and security and the right to respect for private and family life (The Joint Committee on Human Rights, 2021).

Alzheimer Scotland (2022) argue that the current prevalent model of large care homes, with a large number of residents living together, being cared for by a small team of dedicated staff is based on the need to provide quality care economically. With cost the central consideration, they suggest it is the individuals living in the care homes who experience the consequences, as evidenced during the pandemic, where the doors to care homes were shut and individual residents were being isolated in their bedrooms as a form of mitigating risk. As a result of the experiences during the pandemic, the Joint Committee on Human Rights (2021) has called for legislation for an individual risk assessment before placing blanket restrictions upon residents. This is consistent with a human rights approach, which resists restriction without individual justifications. Alzheimer Scotland have gone further and suggested that a new approach to the care home model is required, with a smaller number of people co-living in an environment designed to meet their high care needs, and one which can withstand the ongoing threats of future pandemics without the detrimental consequences to PLWD and their loved ones that have occurred during COVID-19. The care environments in the homes taking part in Study 1 perhaps go some way towards this, but the new model would require dedicated staffing for each living unit to maintain its integrity.

Reflections on the fieldwork carried out

Collecting data from care homes presents many challenges; much consideration needs to be given to the planning of the data collection with very little knowledge on how this will play out in reality. During this project I also recruited one additional home, from a different organisation, that was not ultimately included in the project. Again, this was a home that had won national awards for its design. Although recruiting the home through consultation with the organisation provider and the management team was successful, implementing the data collection at their facility was unsuccessful. Despite the support of the organisation for the area of research, they could not commit to the partnership element of the data collection, which is an essential part of research in care homes. Unfortunately, despite considerable efforts, the care staff and relatives were not formally introduced to the project, often resulting in myself as the researcher unable to access entry into the home, due to their security measures.

As a researcher, being accepted to take part in a care home’s everyday life is a privilege in itself. However, the initial partnership agreement is very much the beginning of the process. In order to carry out the data collection successfully, there must be clear communication with all of the relatives and staff members at the care homes. Prior to data collection in Study 1, I was invited to relatives-resident meetings at the partner organisation, where families were given the opportunity to ask questions about the research, and what this would bring to the home.

Information was provided to the homes prior the start of the research and the researcher completed a staff induction day, working a shift at the homes. However, many of the care staff were still unaware of the research despite efforts to send information in advance and completing the induction. Naturally, it took time to build a rapport with the care staff as they were concerned about being judged by an outsider of any kind, and whether they were permitted by their managers to partake. Additionally, several staff members required reassurance that anything they shared at interview would not be discussed with their employers. Several staff members also expressed that they didn't feel they would have anything to contribute, despite having worked in care or at the home for some time. Furthermore, arranging with care staff who wanted to take part in the project could take several attempts. Despite making prior arrangements with care staff, arrangements would be dependent on the staffing levels on the day, incidents that occurred, general workload, and having the agreement with their colleagues, to take the time 'out'.

Building a rapport with the families was easier as they had the time to discuss the project and they seemed to appreciate being listened to by someone as an outsider of the organisation. Naturally there are family members who were understandably conscious of the presence of an outsider and required further information regarding the researcher's role and that observations would take place in public spaces only. It was important to accept that not everybody would be welcoming of the project and respecting their right not to engage. Despite this, relatives who initially were not interested in the project did participate, having spent some time with them and their relatives on the households. However, in Study 2, there were family members who declined to take part, due to an ongoing issue with the care home organisation, despite being welcoming of me as an individual and as a person that they could talk to, outside of the immediate care home team.

Often families wanted reassurance that I would be a familiar face in the home and that my intentions were to build on the knowledge regarding the lives of people living with advanced dementia in care homes. One relative in Study 1 expressed *'nobody is interested in these,* (referring to the residents)*...nobody'* on my induction shift at the particular care home. However, after spending time on the household, attending afternoon tea and activities, the relative was more than willing to take part, and often invited me for a cup of tea!

Families in Study 1 especially, wanted to ensure that my study would not be representative of the negative media reports on care staff, and that the value of the care staff would be respected. During the fieldwork I spent time getting to know individual families and the residents. Often, spouse participants would invite me to look over their photo albums and specific items of importance, they had brought into the home. Each resident in Study 1 had an individual box outside their bedroom, filled with various items, unique and personal to them; many family members would talk me through the chosen items, reflective of the residents' life experiences and personality.

For a number of relatives, being part of this project was the first opportunity they had been given to talk about their experiences as family carers and they were incredibly supportive of my research. One relative expressed, that they were reassured by my presence at the home

"Being a part of this research project has made a difference to my life. I don't feel so alone anymore. I don't feel so guilty about always talking about my John. There is now someone extra who's there, who I know is looking out for my John" (Relative, Study 1)

Despite many positive experiences during the data collection phase, issues did arise during the fieldwork, where instances needed to be reported to the care home management team for action. Having to balance the role of 'non-judgmental observer' with that of 'whistle-blower' when having witnessed interactions that could constitute 'personal detractions' in Kitwood's terms, devaluing the resident, is no easy task even with clear agreements in advance on procedures to follow (Stake, 2005, p.459). Being placed in such a position as a researcher is emotionally and physically challenging, and I personally questioned my role as a researcher on this project. Furthermore, reporting such incidents does inevitably create tension in the partnership that has been built, and reverses somewhat the rapport that has been built within the home, with care staff naturally wary of your presence, with a number of care staff no longer welcoming of the project.

Nevertheless, being welcomed and accepted into the care home community and the daily lives of residents, relatives and care staff is a privilege. Further, becoming part of the community I was able to fully appreciate and respect the daily challenges presented to care staff and care home organisations. I am grateful for all that the care homes have contributed to this thesis, my learning and to my personal experiences as a researcher and as an individual.

Strengths & Limitations

The study has cast a light on the daily lived experiences of people living with advanced dementia in care homes. The findings have demonstrated that indicators of QoL and well-being can be observed in the later stages of the illness, as well as the factors influencing QoL.

Study 1 included two in-depth case studies of care home residents, Martha and Graham, where I was able to provide evidence of their daily lived experiences at the Care Homes. Importantly, the study has shown how the person remains unique and individual, distinct from other residents, despite their shared dementia diagnosis. Further, the study has demonstrated how making ‘small’ changes to everyday practices, can support the residents’ QoL and well-being. This thesis has demonstrated the importance of including people living with advanced dementia in research, and exploring their daily lived experiences, highlighting key factors that can contribute to QoL.

The study has provided an opportunity for relatives and care staff to share their knowledge and experiences, allowing them to tell their own story and has indicated their willingness to partake in research. A key strength of the study was the rich and in-depth qualitative data that was provided by the families and care staff. The relationships built with participating care homes allowed for the researcher to become part of the home community, allowing for the researcher to gain a deeper understanding of the daily practices, relationships, challenges and observation of the themes in practice.

In Study 2, I could explore and extend the scope of my initial findings from Study 1, to also include two additional fieldwork settings, that were markedly different. The fieldwork in Study 2 reflected experiences of families and care staff, in settings that were not specifically designed to provide dementia care. Additionally, Care Home 1 highlighted the experiences of those in a transitioning home, reflecting the challenges and complexities of these situations, on key stakeholders, residents’ care staff and families.

I must acknowledge that the exploratory nature of this research gave rise to several limitations. I have included only two in-depth case studies, reflecting only the experiences of two individuals living with advanced dementia. Graham and Martha are both unique, with individual relationships, and their experiences are not reflective of all the residents in Study 1. A major limitation to be acknowledged is the lack of resident participation in Study 2, reflecting only the views of relatives and care staff. However, there was a need to balance the thesis in the given timeframe, and to complete further observations in Study 2 would not have allowed me to expand on the qualitative findings in Study 1. Ideally, the Awarecare tool would also have been used in Study 2, to provide a further perspective on residents and their experiences.

In Chapter 6, I must acknowledge that the small sample size limited the statistical power and exploration of the results. Further, from a methodological perspective, many comparisons were made between Care Home 1 and Care Home 2. Stake (2005, p.457) cautions against over-emphasis on comparisons. However, the cases were selected purposively, providing a wider range of contexts than in Study 1, and demonstrating the experiences of those in different contexts.

Importantly, several relatives that could have taken part in this project declined or did not respond to the invitation to participate, limiting the range of relatives taking part. Further, several family members who did not have regular involvement at the care home did not partake in this project. Therefore, I cannot account for the experiences of relatives who do not remain involved, or the impact on the residents of having a more distant relative. In the thesis the perspectives of relatives visiting on a daily basis and those visiting regularly but not daily are reflected. The situation of those residents without family, relying entirely on staff to monitor and advocate, was beyond the scope of this work, but is an essential area to explore.

Lastly, I must acknowledge that I did not succeed in presenting the findings of Study 2 back to the participants for participant validation, although this was planned, this was not possible due to logistical reasons.

Directions for future research

This research has highlighted the importance of conducting research with people living with advanced dementia. The results from this current thesis, add to existing literature providing further evidence of factors which contribute to the QoL of residents living with advanced dementia in care homes. However, previous research in this area is lacking, with the focus being on earlier stages, where people are possibly able to provide their own views. Without the knowledge and in-depth understanding of what constitutes QoL of individuals living with advanced dementia, challenges are likely to persist (Brown & Tolson, 2020). According to Brown and Tolson (2020) an exploration of advanced dementia to increase understanding and best care practices is urgently needed. Without development and understanding in this area, it will be difficult to progress in developing better practice.

To extend knowledge in this research area, three avenues are proposed:

1. A larger scale study to gain further involvement of individuals living with advanced dementia in the research, across a wider range of care settings.
2. Consideration of the needs of residents living with advanced dementia in care homes who do not receive regular visits from family or friends. This could explore different approaches to advocacy, care-planning and monitoring.
3. Following this, a further exploration of human rights as a possible training and development initiative for care homes, where rights can be understood at a level they can be easily recognised, demonstrated and applied in everyday practices and procedures.

Conclusion

Interest in living well with dementia is continuously growing however this is yet to extend to people living with advanced dementia, and their quality of life remains underexplored. This study has contributed to the knowledge on quality of life and human rights of people living with advanced dementia in care home settings. The study has shown how quality of life is observable in individuals, even in later stages of the illness where verbal communication is limited. Importantly, I have shown how two individuals living with the illness demonstrated very different ways of expressing their well-being. The study has highlighted families as key partners in care and the positive effect of their involvement on the residents' quality of life and human rights. Further, the study has demonstrated how care home environments and cultures can either support relationships and promote rights to be upheld or create tension, which contributes to the ill-being of residents, relatives and care staff, with significant implications for maintaining and promoting human rights.

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Appendix

Appendix A Ethical Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

**Gwasanaeth Moeseg Ymchwil
Research Ethics Service**

Ariennir gan Llywodraeth Cymru
Funded by Welsh Government

**Pwyllgor Moeseg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor**

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
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17 Febraury 2017

Ms Sian Elen Hughes
Dementia Services Development Centre (DSDC) Wales
Bangor University,
Ardudwy
Bangor, LL57 2PZ psu34d@bangor.ac.uk

Dear Ms Hughes,

Study title:	**The quality of life of people living with advanced dementia: A pilot study**
REC reference:	**17/WA/0015**
IRAS project ID:	**220298**

Thank you for your letter of 14 February 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

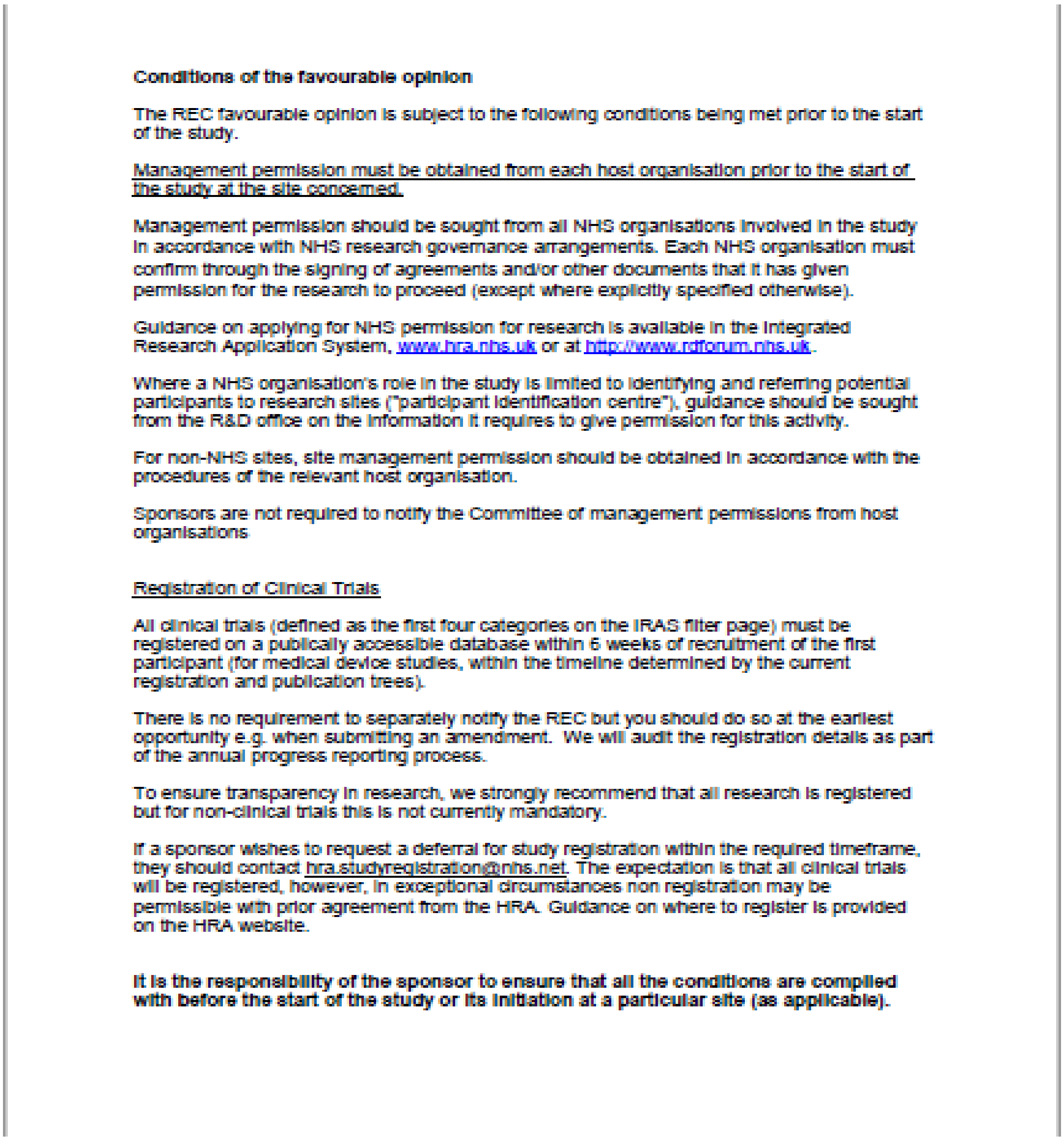
We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Dr Rossela Roberts, rossela.roberts@wales.nhs.uk

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.



Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

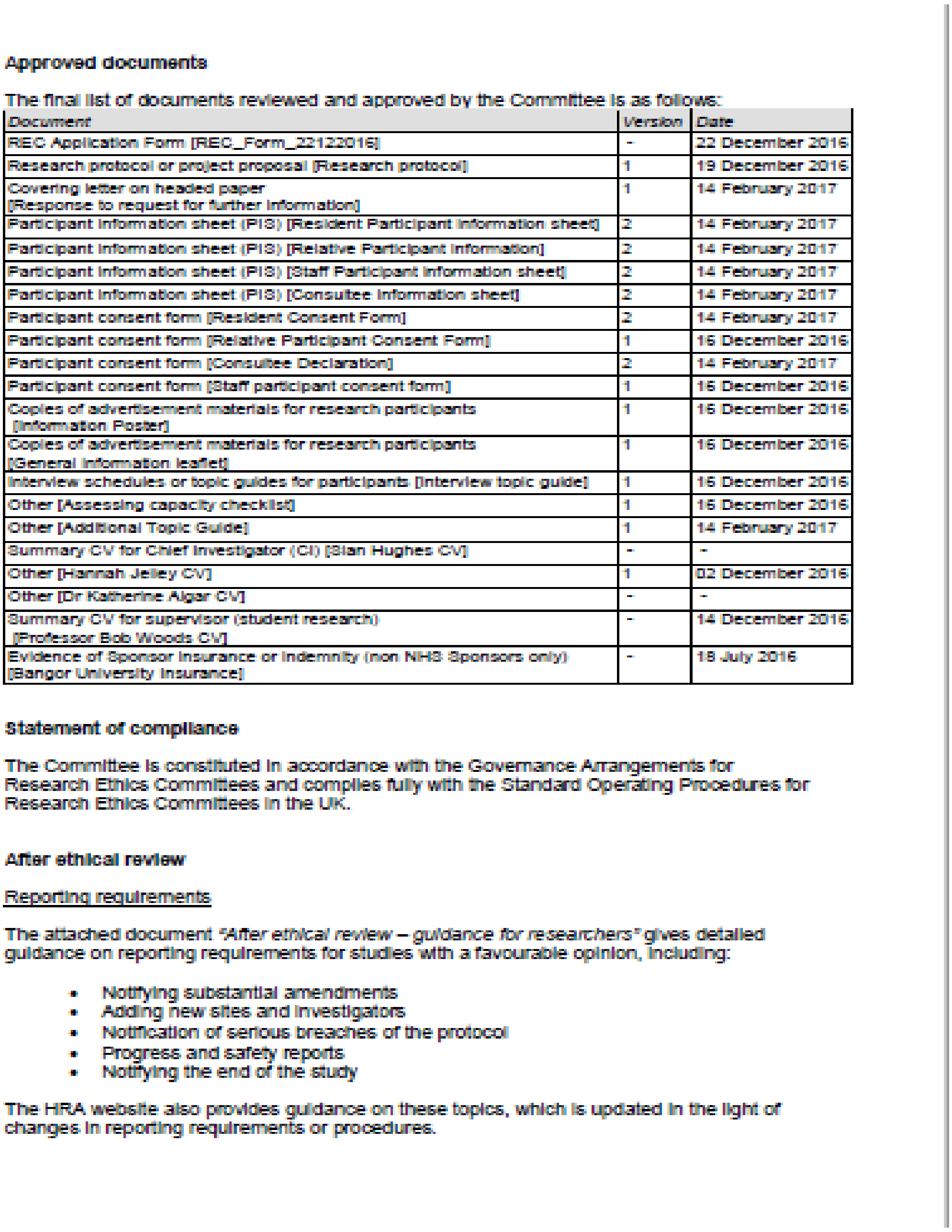
All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).



Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
REC Application Form [REC_Form_22122016]	-	22 December 2016
Research protocol or project proposal [Research protocol]	1	19 December 2016
Covering letter on headed paper [Response to request for further information]	1	14 February 2017
Participant information sheet (PIS) [Resident Participant information sheet]	2	14 February 2017
Participant information sheet (PIS) [Relative Participant information]	2	14 February 2017
Participant information sheet (PIS) [Staff Participant information sheet]	2	14 February 2017
Participant information sheet (PIS) [Consultee information sheet]	2	14 February 2017
Participant consent form [Resident Consent Form]	2	14 February 2017
Participant consent form [Relative Participant Consent Form]	1	16 December 2016
Participant consent form [Consultee Declaration]	2	14 February 2017
Participant consent form [Staff participant consent form]	1	16 December 2016
Copies of advertisement materials for research participants [Information Poster]	1	16 December 2016
Copies of advertisement materials for research participants [General information leaflet]	1	16 December 2016
Interview schedules or topic guides for participants [Interview topic guide]	1	16 December 2016
Other [Assessing capacity checklist]	1	16 December 2016
Other [Additional Topic Guide]	1	14 February 2017
Summary CV for Chief Investigator (CI) [Sian Hughes CV]	-	-
Other [Hannah Jelley CV]	1	02 December 2016
Other [Dr Katherine Algar CV]	-	-
Summary CV for supervisor (student research) [Professor Bob Woods CV]	-	14 December 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Bangor University insurance]	-	18 July 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

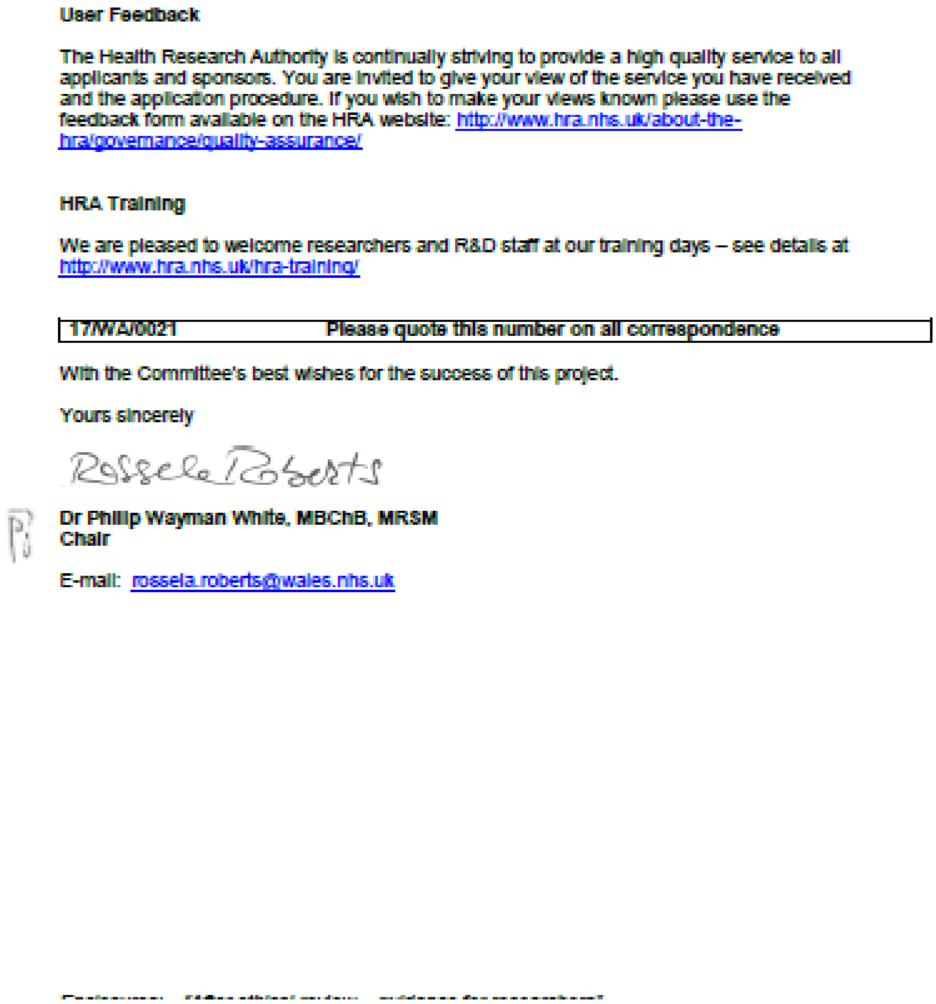
After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.



User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/WA/0021	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

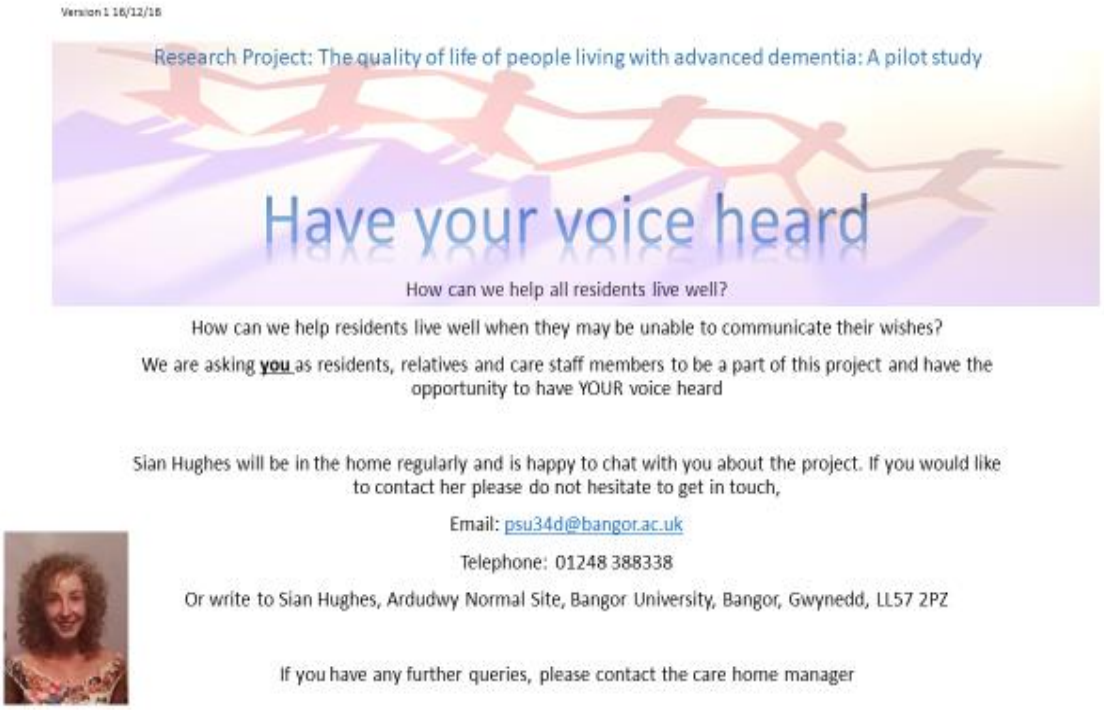
Yours sincerely

Rossela Roberts

Dr Phillip Wayman White, MBChB, MRSM
Chair

E-mail: rossela.roberts@wales.nhs.uk

Appendix B Informal Information Poster



Version 1 16/12/16

Research Project: The quality of life of people living with advanced dementia: A pilot study

Have your voice heard

How can we help all residents live well?

How can we help residents live well when they may be unable to communicate their wishes?

We are asking **you** as residents, relatives and care staff members to be a part of this project and have the opportunity to have YOUR voice heard

Sian Hughes will be in the home regularly and is happy to chat with you about the project. If you would like to contact her please do not hesitate to get in touch,

Email: psu34d@bangor.ac.uk

Telephone: 01248 388338

Or write to Sian Hughes, Ardudwy Normal Site, Bangor University, Bangor, Gwynedd, LL57 2PZ

If you have any further queries, please contact the care home manager

Appendix C: Informal Information leaflet

How can we ensure all residents live well?

Research evidence for quality of life in dementia is increasing. Little is known however, about the quality of life and well-being in the later stages of the illness. We are aiming to add to the current gap in research as it is important to investigate how we can support people in advanced stages of the illness, when a person may find it more difficult to verbally communicate their wishes.

WE ARE LOOKING FOR....

RESIDENTS who are able to give their views on living with dementia in a care home. Where it isn't possible for residents to give their own consent, a relative will be consulted.

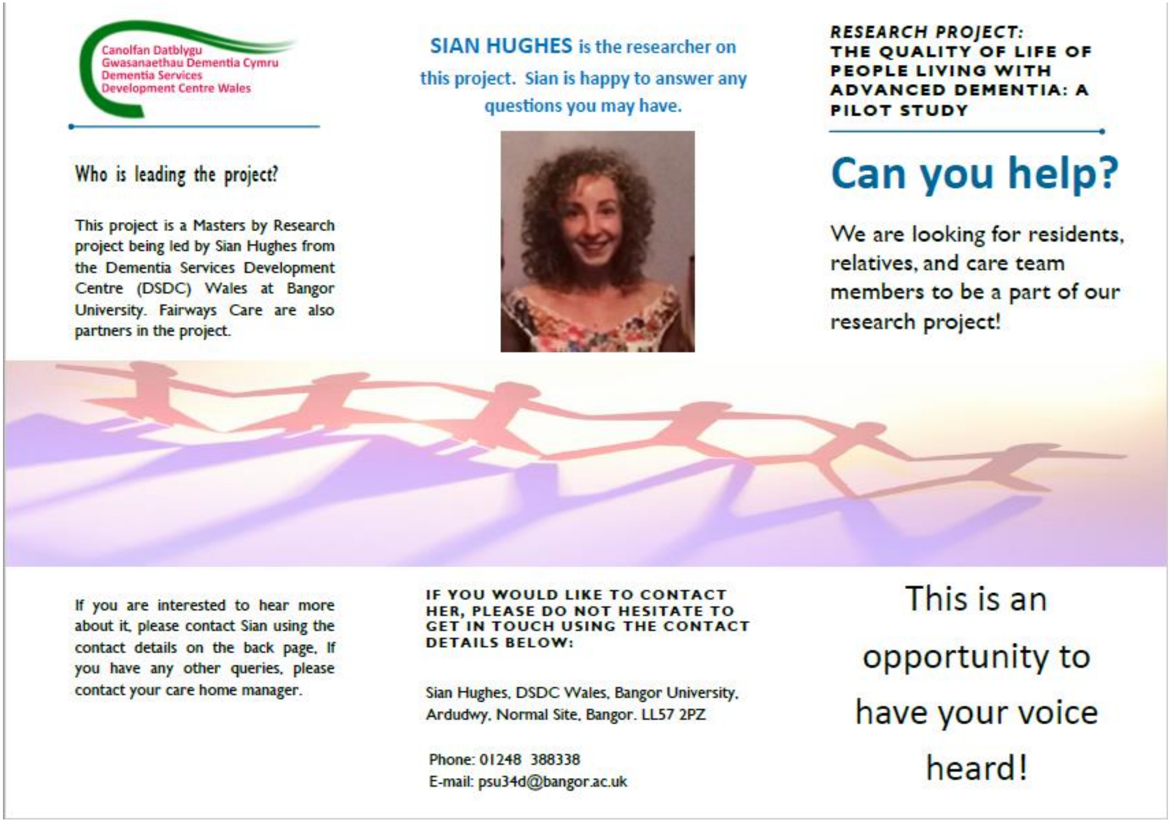
RELATIVES who would like to speak to us about the experiences of your relative living in the care home.

CARE STAFF who would like to speak to us about the individuals you are caring for in the home.

As part of this research project, the researcher will be observing participating residents in communal areas of the home whilst they go about their day-to-day routine.

Before this project begins, the researcher will come and meet with you. No observations will take place of individuals who haven't given prior consent.

Participant Information Leaflet_V1 16/12/16



Canolfan Datblygu Gwasanaethau Dementia Cymru
Dementia Services Development Centre Wales

Who is leading the project?

This project is a Masters by Research project being led by Sian Hughes from the Dementia Services Development Centre (DSDC) Wales at Bangor University. Fairways Care are also partners in the project.

If you are interested to hear more about it, please contact Sian using the contact details on the back page. If you have any other queries, please contact your care home manager.

SIAN HUGHES is the researcher on this project. Sian is happy to answer any questions you may have.

IF YOU WOULD LIKE TO CONTACT HER, PLEASE DO NOT HESITATE TO GET IN TOUCH USING THE CONTACT DETAILS BELOW:

Sian Hughes, DSDC Wales, Bangor University,
Ardudwy, Normal Site, Bangor. LL57 2PZ

Phone: 01248 388338
E-mail: psu34d@bangor.ac.uk

RESEARCH PROJECT:
THE QUALITY OF LIFE OF PEOPLE LIVING WITH ADVANCED DEMENTIA: A PILOT STUDY

Can you help?

We are looking for residents, relatives, and care team members to be a part of our research project!

This is an opportunity to have your voice heard!

Appendix D: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Resident

Quality of life of people living with advanced dementia

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

Why have I been invited?

We are inviting you to take part in this study because you are a resident living with dementia in a care home setting.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. It is important to address how to promote and maintain quality of life, well-being and rights.

The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What does taking part involve

If you agree to take part in this study, we will spend time over a number of days and weeks getting to know you. We will seek to gather your views of how all residents can live well, either through chatting or using communication aids. Observations will also be made in public areas of the home by the researcher, using an existing observational tool, AwareCare. The researcher will observe you during a usual activity that is run by the care home. Every effort will be made to ensure that there is no disruption to the activity by the researcher being present. The research team will ask your permission to look at your medical records, care home records and care plans in order to evaluate the extent to which your needs are being met.

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and to current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia and may help identify meaningful activities for people with severe dementia, which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives.

What are the possible risks and disadvantages of taking part?

We do not consider taking part will involve any disadvantages or specific risks or that it could cause you any harm.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspect of your participation, we would ask you first to speak to one of the research team, so that we can try to address your concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd LL57 2AS. Tel: 01248 383136. E-mail huw.roberts@bangor.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. It is stored securely and without any identifying details. Any personal details are kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records. The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your health, safety or well-being. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

We will also ask your permission for us to store in anonymised form the information that we collect from you for long-term use by the research team. This would mean that the information can be shared with accredited researchers in future so that they might understand more and learn from the information we collect also. No-one would ever be able to identify you personally from the archived information.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time without giving a reason. Withdrawing from the study will not affect your care in any way. We will continue to use the information collected about you before you decided to withdraw, unless you inform us that you do not wish for us to do so.

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programme by Bangor University on behalf of the Welsh higher education sector. The project funding partner is Mark Bailey managing director at Fairways Care Ltd. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University and the Wales Research Ethics 5 (Bangor) Committee.

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Phone: 01248 383719

Dr Huw Roberts

School Manger,

School of Healthcare sciences

Bangor

LL57 2AS

Phone: 01248 383136.

Thank you for considering taking part in this research study!

Appendix E: Participant information sheet

PRIFYSGOL
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PARTICIPANT INFORMATION SHEET

Relatives

Quality of life of people living with advanced dementia

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

Why have I been invited?

We are inviting you to take part in this study because you are a relative of an individual living with dementia in a care home setting.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. It is important to address how to promote and maintain quality of life, well-being and rights. The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your relative receives.

What does taking part involve?

If you agree to take part in this study, the researcher will invite you to partake in an interview which could last approximately 1 hour. This will take place at a convenient time in the care home. Before this interview the researcher will discuss with you the topics of the questions and check that you are happy to continue.

It would help the researcher to audio record interviews. Before the recorder is switched on, the researcher will ask you if you are willing for the interview to be recorded. If you do not wish for your interview to be recorded, you may still take part. Once the conversation has been typed up, the audio-recording will be deleted. Your name will not be linked to any transcripts. The research team will also ask permission to look at your relatives medical records, care home records and care plans to see how personalized care and needs are being maintained

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia. It is possible that the research will identify meaningful activities for people with severe dementia which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives.

What are the possible risks and disadvantages of taking part?

We do not consider taking part will involve any disadvantages or specific risks or that it could cause you any harm.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspect of your participation, we would ask you first to speak to one of the research team, so that we can try to address your concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd LL57 2AS. Tel: 01248 383136. E-mail huw.roberts@bangor.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. It is stored securely and without any identifying details. Any personal details are kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records. The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your or your relative’s health, safety or well-being. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

We will also ask your permission for us to store in anonymised form the information that we collect from you for long-term use by the research team. This would mean that the information can be shared with accredited researchers in future so that they might understand more and learn from the information we collect also. No- one would ever be able to identify you personally from the archived information.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time without giving a reason. Withdrawing from the study will not affect you in any way. We will continue to use the information collected about you before you decided to withdraw, unless you inform us that you do not wish for us to do so.

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programme by Bangor University on behalf of the Welsh higher education sector. The project funding partner is Mark Bailey managing director at Fairways Care Ltd. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University and the Wales Research Ethics Committee 5 (Bangor).

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Phone: 01248 383719

Dr Huw Roberts

School Manger,

School of Healthcare sciences

Bangor

LL57 2AS

Phone: 01248 383136

Thank you for considering taking part in this research study!

Appendix F: Participant Information Sheet

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PARTICIPANT INFORMATION SHEET

Staff member

Quality of life of people living with advanced dementia

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

Why have I been invited?

We are inviting you to take part in this study because you are a staff member caring for an individual living with dementia in a care home.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. As it is important to address how to promote and maintain quality of life, well-being and rights. The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not result in any implications at your place of work.

What does taking part involve?

If you agree to take part in this study, the researcher will invite you to partake in an interview which could last approximately 1 hour at a convenient time during your shift in the care home. Before this interview the researcher will discuss with you the topics of the questions and check that you are happy to continue.

It would help the researcher to audio record interviews. Before the recorder is switched on, the researcher will ask you if you are willing for the interview to be recorded. If you do not wish for your interview to be recorded, you may still take part. Once the conversation has been typed up, the audio-recording will be deleted. Your name will not be linked to any transcripts. The research team will also ask permission to look resident at medical records, care home records and care plans to see how personalized care and needs are being maintained

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia. It is possible that the research will identify meaningful activities for people with severe dementia which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives.

What are the possible risks and disadvantages of taking part?

We do not consider taking part will involve any disadvantages or specific risks or that it could cause you any harm.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspect of your participation, we would ask you first to speak to one of the research team, so that we can try to address your concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd LL57 2AS. Tel: 01248 383136. E-mail huw.roberts@bangor.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. It is stored securely and without any identifying details. Any personal details are kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records. Information and answers that are provided during interviews will be kept confidential and will be anonymized. There will be no link to your identity and your given answers.

The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your or a resident's health, safety or well-being. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

We will also ask your permission for us to store in anonymised form the information that we collect from you for long-term use by the research team. This would mean that the information can be shared with accredited researchers in future so that they might understand more and learn from the information we collect also. No-one would ever be able to identify you personally from the archived information.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time without giving a reason. If you wish to withdraw from the research, there will be no implications at your place of work. We will continue to use the information collected about you before you decided to withdraw, unless you inform us that you do not wish for us to do so.

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programmed by Bangor University on behalf of the Welsh higher education sector. The project funding partner is Mark Bailey managing director at Fairways Care Ltd. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University and Wales Research Ethics Committee 5 (Bangor).

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Dr Huw Roberts

School Manger,

School of Healthcare sciences

Bangor

LL57 2AS

Phone: 01248 383719 Phone: 01248 383136.

Email: b.woods@bangor.ac.uk Email :huw.roberts@bangor.ac.uk

Thank you for considering taking part in this research study!

Appendix G: Nominated Consultee Information Sheet

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The quality of life of people living with advanced dementia: A pilot study

PERSONAL / NOMINATED CONSULTEE INFORMATION SHEET

Introduction

A person with dementia is being invited to take part in a research study, but is thought to lack the capacity to give consent on his/her own behalf. We would therefore like to ask your advice regarding whether this person should participate. In particular, we would like to know what you think this person's feelings and wishes would be with regard to taking part. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide this person would have no objection to taking part, we will ask you to read and sign the consultee declaration on the last page of this information sheet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think he/she should be withdrawn.

If you decide that this person would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice. We will understand if you do not want to take on this responsibility.

Before you give advice, it is important that you understand what the research will involve for this person and why it is being done. Please take time to read the following information and discuss it with others if you wish. Ask us if there is anything that is not clear or if you require further information about this study. Take your time in deciding whether this person would wish to take part.

Thank you for reading this information sheet.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. It is important to address how to promote and maintain quality of life, well-being and rights. The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia.

Why has this person been invited?

This person has been invited as they are living with advanced dementia in a care home setting and we need people with advanced dementia to add to the current knowledge base.

Does this person have to take part?

This person does not have to take part. It is up to you to advise whether or not this person should be included. If you do decide that he/she would wish to participate, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to change your advice at any time without giving a reason. A decision to withdraw this person at any time, or advice that he/she should not to take part, will not affect the standard of care that he/she receives.

What will this person have to do?

If you agree for this person to take part in this study, we will spend time over a number of days and weeks getting to know them. We will seek to gather his/her views of how all residents can live well, either through chatting or using communication aids. Observations will also be made in public areas of the home by the researcher, using an existing observational tool, AwareCare. The researcher will observe this person during a usual activity that is run by the care home. Every effort will be made to ensure that there is no disruption to the activity by the researcher being present. The research team will ask your permission to look at the residents' medical records, care home records and care plans in order evaluate the extent to which their needs are being met.

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

What are the possible disadvantages and risks of taking part?

No risk to participants is anticipated during this research study and we would not expect any harmful effects from observations and interviews with participants. Should any of the participants feel uncomfortable or distressed they will be supported by the research team. Additionally, participants will be made aware that they are free to withdraw from participation at any time.

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia and may help identify meaningful activities for people with severe dementia, which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives.

Will this person's taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about him/her will be handled in confidence. All data is stored without any identifying details under secure conditions. The only people who will have access to view identifiable data is the researcher and supervisor. Confidentiality would only ever be broken if there was a concern that the person might be at risk of harm.

What will happen if this person doesn't want to continue with the study?

He/she will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care he/she receives.

What if there is a problem?

If you are unhappy or dissatisfied about any aspect of this person's participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response, you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd. LL57 2AS. Tel: 01248 383136. Email: huw.roberts@bangor.ac.uk

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programme by Bangor University on behalf of the Welsh higher education sector. The project funding partner is Mark Bailey managing director at Fairways Care Ltd. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University and the Wales Research Ethics Committee 5 (Bangor).

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods
DSDC Wales, Bangor University
Ardudwy, Normal Site,
Bangor
LL57 2PZ
Phone: 01248 383719
Email: b.woods@bangor.ac.uk

Dr Huw Roberts
School Manger,
School of Healthcare sciences
Bangor
LL57 2AS
Phone: 01248 383136.
Email :huw.roberts@bangor.ac.uk

Thank you for considering this information!

Appendix H: Participant Consent Form

PRIFYSGOL
BANGOR
UNIVERSITY

The quality of life of people living with advanced dementia: A pilot study

PARTICIPANT CONSENT FORM

Resident

1. I confirm that I have read and understand the information sheet (Version 2) for the above study. I have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my care or legal rights in any way. ☐
3. I agree that if I withdraw from the study that the research team may continue to use information that I had previously provided. ☐
4. I understand that my medical and care home records and individual care plan may be looked at by members of the research team or by individuals from regulatory authorities where it is relevant to my taking part in this research. I give my permission for my medical and care home records and care plan to be accessed in this way. ☐
5. I understand that all information given by me or about me will be treated as confidential by the research team. I understand that information provided by me or about me will only be used for research purposes and my personal details will be treated with the strictest confidence. ☐

6. I understand that all information given by me or about me will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

7. I understand that if the research team observe anything that causes any serious concern about my health, safety or well-being, they have a duty to inform an appropriate professional. ☐

8. I understand that the researchers will be making observations during my daily routines and activities within public areas of the care home ☐

9. I agree to take part in the above study. ☐

Name of Participant Date Signature

....

Researcher Date Signature

....

OFFICE USE ONLY:

Participant Identification number: ☐☐☐☐

Appendix I: Participant Consent Form

PRIFYSGOL
BANGOR
UNIVERSITY

The quality of life of people living with advanced dementia: A pilot study

PARTICIPANT CONSENT FORM

Relatives

Please initial boxes for all statements you agree to

1. I confirm that I have read and understand the information sheet (Version 2) for the above study. I have had the opportunity to consider the information and ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my relatives care in any way ☐

3. I agree that if I withdraw from the study that the research team may continue to use information that I had previously provided. ☐

4. I understand that all information given by me or about me will be treated as confidential by the research team. I understand that information provided by ☐

me or about me will only be used for research purposes and my personal details will be treated with the strictest confidence.

5. I understand that all information given by me or about me will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

6. I understand that if the research team observe anything that causes any serious concern about my or my relative's health, safety or well-being or concerns regarding my relative, they have a duty to inform an appropriate professional. ☐

7. I understand that some interviews will be audio recorded for later analysis purposes only. Where these interviews are transcribed, any personal details will be anonymised so that I cannot be identified. I agree to my interview being audio recorded. ☐

8. I agree to take part in the above study. ☐

Name of Participant Date Signature

....

Researcher Date Signature

…………………………………………………… ………………………… ………………………………..

OFFICE USE ONLY:

Participant Identification number:

Appendix J: Participant Consent Form

PRIFYSGOL
BANGOR
UNIVERSITY

The quality of life of people living with advanced dementia: A pilot study

PARTICIPANT CONSENT FORM

Staff Members

Please initial boxes for all statements you agree to

1. I confirm that I have read and understand the information sheet (Version 2) for the above study. I have had the opportunity to consider the information and ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect employment at the home in any way ☐

3. I agree that if I withdraw from the study that the research team may continue to use information that I had previously provided. ☐

4. I understand that all information given by me or about me will be treated as confidential by the research team. I understand that information provided by ☐

me or about me will only be used for research purposes and my personal details will be treated with the strictest confidence.

5. I understand that all information given by me or about me will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

6. I understand that if the research team observe anything that causes any serious concern about my health, safety or well-being, or concerns regarding residents, they have a duty to inform an appropriate professional. ☐

7. I understand that some interviews will be audio recorded for later analysis purposes only. Where these interviews are transcribed, any personal details will be anonymised so that I cannot be identified. I agree to my interview being audio recorded. ☐

8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
....	....	....
Researcher	Date	Signature

………………………………………………………… ………………………… ………………………………….

OFFICE USE ONLY:

Participant Identification number:

Appendix K: Consultee Declaration Form

PRIFYSGOL
BANGOR
UNIVERSITY

The quality of life of people living with advanced dementia: A pilot study

CONSULTEE DECLARATION FORM

Please initial boxes for all statements you agree to

1. I ………………………………..[name of consultee] have been consulted about ……………………………….....[name of potential participant]'s participation in this evaluation. I have read and understand the

   information sheet (Version 2) for the above study I have had the opportunity to ask questions about the study and understand what is involved. ☐

2. In my opinion he/she would have no objection to taking part in the above study. ☐

3. I understand that participation is voluntary and that I am free to request he/she is withdrawn at any time, without giving any reason. I understand that if he/she withdraws this will not affect his/her care or legal rights in any way. ☐

4. I agree that if the participant is withdrawn from the study that the research team may continue to use information previously provided. ☐

5. I understand that his/her medical and care home records and care plans may be looked at by members of the research team or individuals from regulatory authorities where it is relevant to participation in this research. I give my permission for these individuals to have access to his/her records. ☐

6. I understand that all information about the participant will be treated as confidential by the research team. I understand that information provided will only be used for research purposes and personal details will be treated with the strictest confidence. ☐

7. I understand that all information will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

8. I understand that if the research team observe anything that causes any serious concern about this person's health, safety or well-being, they have a duty to inform an appropriate professional. ☐

9. I understand that the researchers will be making observations during daily routines and activities within public areas of the care home. In my opinion, he/she would have no objection to being observed. ☐

Name of Participant

………………………………………………………………………………

Name of Consultee Date Signature

....

Researcher Date Signature

....

OFFICE USE ONLY: Participant Identification number:

Appendix L: Interview Topic Guide

The quality of life of people living with advanced dementia: A pilot study

Interview topic guide

Introduction

OK, before we begin the interview itself, I'd like to confirm that you have read and signed the informed consent form, that you understand that your participation in this study is entirely voluntary, that you may refuse to answer any questions, and that you may withdraw from the study at any time.

- Introduction to the chief researcher and Dementia Services Development Centre (DSDC) Wales, Bangor University

- Explanation of the aims of the research project

- Explanation of confidentiality and anonymity

- Explanation of the audio recorder, length of time of the discussion and the nature of the questions, advise that they may withdraw at any time without a reason

- Check to see if they have any questions

- Check to see if they are happy to continue

Topics/Questions

- How is well-being/qol expressed in the individuals?
  What are the signs?
    - Explore

- Well-being/QOL – How it's monitored?

- If you are making a decision on the individual's behalf, **what is the reason for this? (Why?)**

- How do you know when you are making a decision on this person's behalf - that this is the best decision for that individual?

- What is the assumption do you make about the individuals ability to make decisions about their daily lives

    - Explore perception
    - Explore responsiveness

- Human rights in advanced dementia/care home setting **(views)**

- What are your views and experiences on Human Rights in advanced dementia in care home settings?

- Does living in a care home make a difference to living in the community?

Conclusion:

- Thank the participant and reiterate that the interview will be confidential and that any of the data will not have their names attached. Any personal identifiers will be anonymised during transcription.

- Provide
- contact details in case they want to get in touch later

Appendix M: Assessing Capacity

The quality of life of people living with advanced dementia: A pilot study Checklist: Assessing Capacity

Participant ID: ________________________

Participant can:

- Understand the information relevant to the decision. ☐

  AND
- Retain the information. ☐

  AND
- Use or weigh the information to arrive at a choice. ☐

  AND
- Communicate the decision ☐

*****failure on any part indicates a lack of capacity***

NOTE: ____

____

____

Researcher	Date	Signature
____________________	_________________	________________________

Appendix N: Substantial Amendments Application

Substantial amendments covering letter

Rossela Roberts,
RES Manager,
Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

September 28th 2017

Dear Rossela,

Research study title: The Study title: The quality of life of people living with advanced dementia: A pilot study

REC reference: 17/WA/0015 IRAS project ID: 220298

As per the ethics guidelines I am writing to you to inform you of amendments to the project.

1) Initial project dates (January 2017 - October 2017) as the project has been extended from the Masters by Research to a full PhD programme, we require additional time at sample sites (October 2019)
2) Recruitment of additional research sites to include XXXXX and XXXXX
3) Additional quantitative measures to explore carers' well-being as measured by Warwick Edinburgh Mental-Well Being Scale (WEMBS) and Zarit Burden Interview (ZBI) Satisfaction With Care at the End of Life in Dementia (SWC-EOLD).
4) Further questions have been included in the interview topic guide
5) The Masters by Research (October 2016 - October 2017) has been funded by company partner Fairways Care Ltd. As the project is now going forward as a PhD the funding is being provided by the Drapers Company

6) As part of PhD outputs the training workshop management teams will be informed how best to safeguard staff wellbeing in the context care homes. Areas where staff may need more support to carry out their roles more effectively will be identified

Changes have been made to documents

Minor changes have been made to the documents which are highlighted in the documents under the subheadings outlined below.

Resident participant information sheet

- Project title
- What is the purpose of this study?
- What does taking part involve?
- What are the possible benefits of taking part?
- Who is organizing this research?

Nominated consultee participant information sheet

- Project title
- What is the purpose of this study?
- What does taking part involve?
- What are the possible benefits of taking part?
- Who is organizing this research?

Relative participant information sheet

- Project title
- What is the purpose of this study?
- What does taking part involve?
- What are the benefits of taking part?
- Who is organizing this research?

Staff member participant information sheet

- Project title
- What is the purpose of this study?
- What does taking part involve?
- What are the possible benefits of taking part?
- Who is organizing this research?

Consent forms

Changes made to resident, relative, consultee and staff consent forms

- Project title

Informal leaflet

- Project title
- Who is leading the project?
- Care staff

Interview topic guide

- Project title
- Additional questions

Research Protocol

- Project Title

Background

The proposed PhD application builds on the existing work completed as part of the Master's by Research centered on '*The quality of life of people living with advanced dementia: A pilot study'* by Sian Hughes, supported by the team at DSDC, led by Professor Bob Woods.

Aims and Objectives

As this PhD is building on the Masters project, the project aims to explore wellbeing of the staff carers, as measured by the Warwick Edinburgh Mental-Well Being Scale (WEMBS) and Zarit Burden Interview (ZBI). It has been consistently recognized that caring for individuals with advanced dementia can lead to increased stress, distress and burden levels. Thus, knowledge of staff wellbeing may identify ways of alleviating stress, which may have significant impact on how they provide care A third aim of the project is to explore family satisfaction with residents care employing the Satisfaction With Care at the End of Life in Dementia (SWC-EOLD). Care homes are a major site in care of individuals living with advanced dementia. Addressing family satisfaction is fundamental to providing high quality care. Further, we aim to look at the family involvement, or lack of, in residents care planning. Current research suggests family involvement in care planning improves comfort and satisfaction especially within end-of-life care within advanced dementia (Engel et al., 2006)

Participants

Inclusion Criteria

Relatives: Additionally relatives who do not have regular contact with the resident will be invited to partake.

The following key questions will be addressed:

How do care workers or family members communicate with people with advanced dementia and what methods are being used?

How does the way care staff feel about their jobs affect how they interact with the residents?

How can relatives and staff protect rights and enable choices for people with advanced dementia?

How can residents without regular family involvement be supported?

How are families involved in the care planning of the resident?

Design and measures

Quantitative

As this PhD is building the Masters project, the project aims to explore wellbeing the staff carers, as measured by the Warwick Edinburgh Mental-Well Being Scale (WEMBS) and Zarit Burden Interview (ZBI). It has been consistently recognized that caring for individuals with advanced dementia can lead to increased stress, distress and burden levels. Thus, knowledge of staff wellbeing may identify ways of alleviating stress, which may have significant impact on how they provide care. Additionally, relatives will be asked to complete Satisfaction With Care at the End of Life in Dementia (SWC-EOLD).

Qualitative Measures

Relatives of residents: Further, relatives will have the opportunity to discuss family involvement in care planning and care satisfaction

Care staff: Staff will have the opportunity to talk about their roles, interactions with the residents and the impact this may have upon the residents.

Recruitment of sample sites: Recruitment of additional sample sites - Additional care homes in Wales will be identified as part of the Phase 2 fieldwork sites, building on the existing work completed as part of the Masters by Research. Additional research sites will include XXXXX

Assessment and Procedure

Observations may show that the use of alternative communication methods such as ‘Talking Mats’ may initiate more interaction between care staff/relatives with the residents – which would be significant in QOL and well-being

Focus groups with people with dementia, their relatives and care staff will be conducted to explore knowledge of human rights and how choices are enabled in

the care homes.

Data analysis

Warwick Edinburgh Well-Being Scale (WEMWBS)

The WEMWBS will be used to explore care staff well-being. The total score is obtained by summing the score for each of the 14items. The latter ranges from 1 – 5 and the total score from 14-70.

Zarit Burden Interview is employed to address personal strain and role strain. The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). Higher scores will indicate a higher sense of burden.

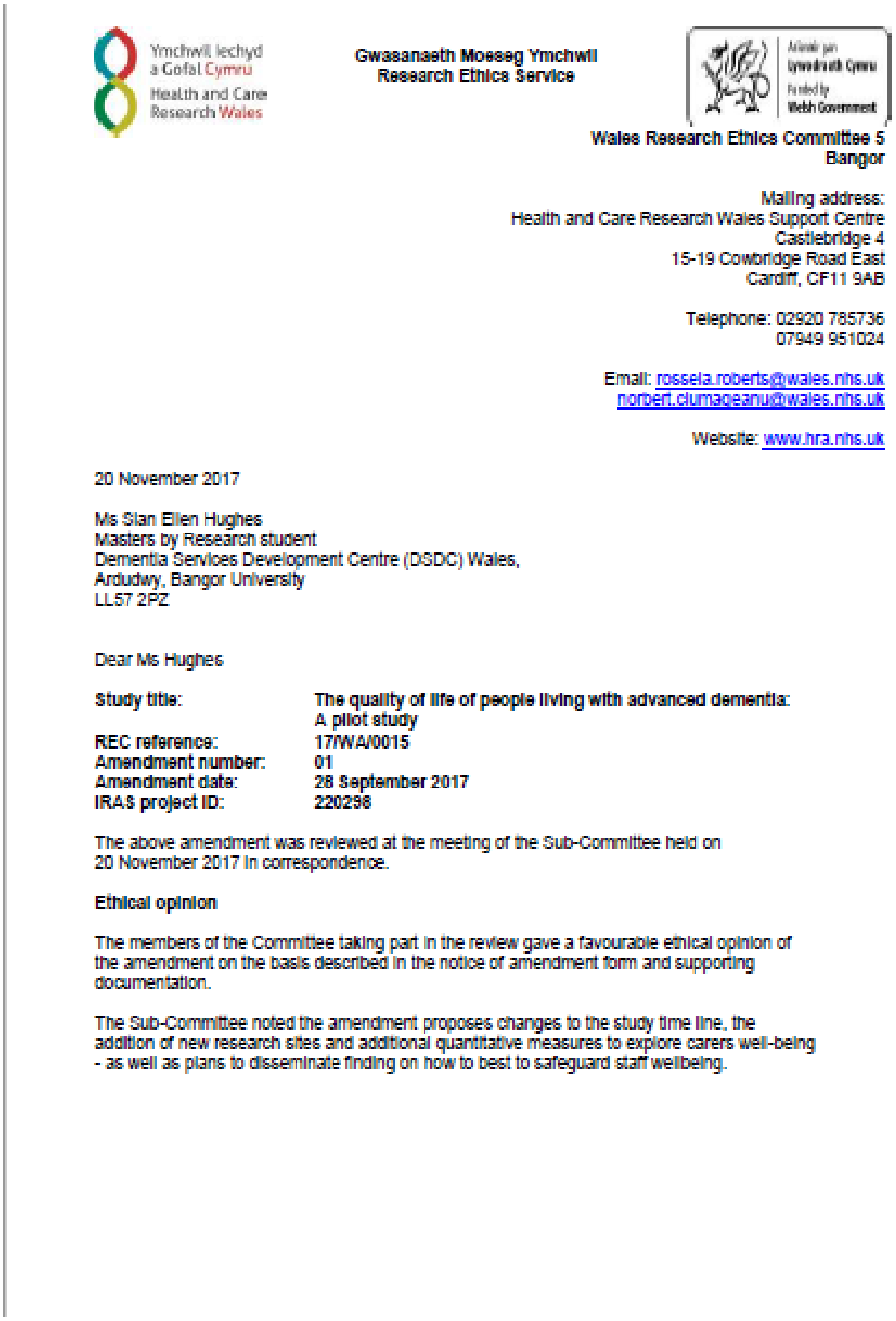
Satisfaction with end of life in dementia scale, the possible scores of this scale range from 10-40 with a higher score indicating higher satisfaction

We look forward to hearing from you,

Yours sincerely,

Sian Hughes

Appendix O: Substantial Amendments Approval



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 5
Bangor

Mailing address:
Health and Care Research Wales Support Centre
Castlebridge 4
15-19 Cowbridge Road East
Cardiff, CF11 9AB

Telephone: 02920 785736
07949 951024

Email: rossela.roberts@wales.nhs.uk
norbert.ciumageanu@wales.nhs.uk

Website: www.hra.nhs.uk

20 November 2017

Ms Sian Ellen Hughes
Masters by Research student
Dementia Services Development Centre (DSDC) Wales,
Ardudwy, Bangor University
LL57 2PZ

Dear Ms Hughes

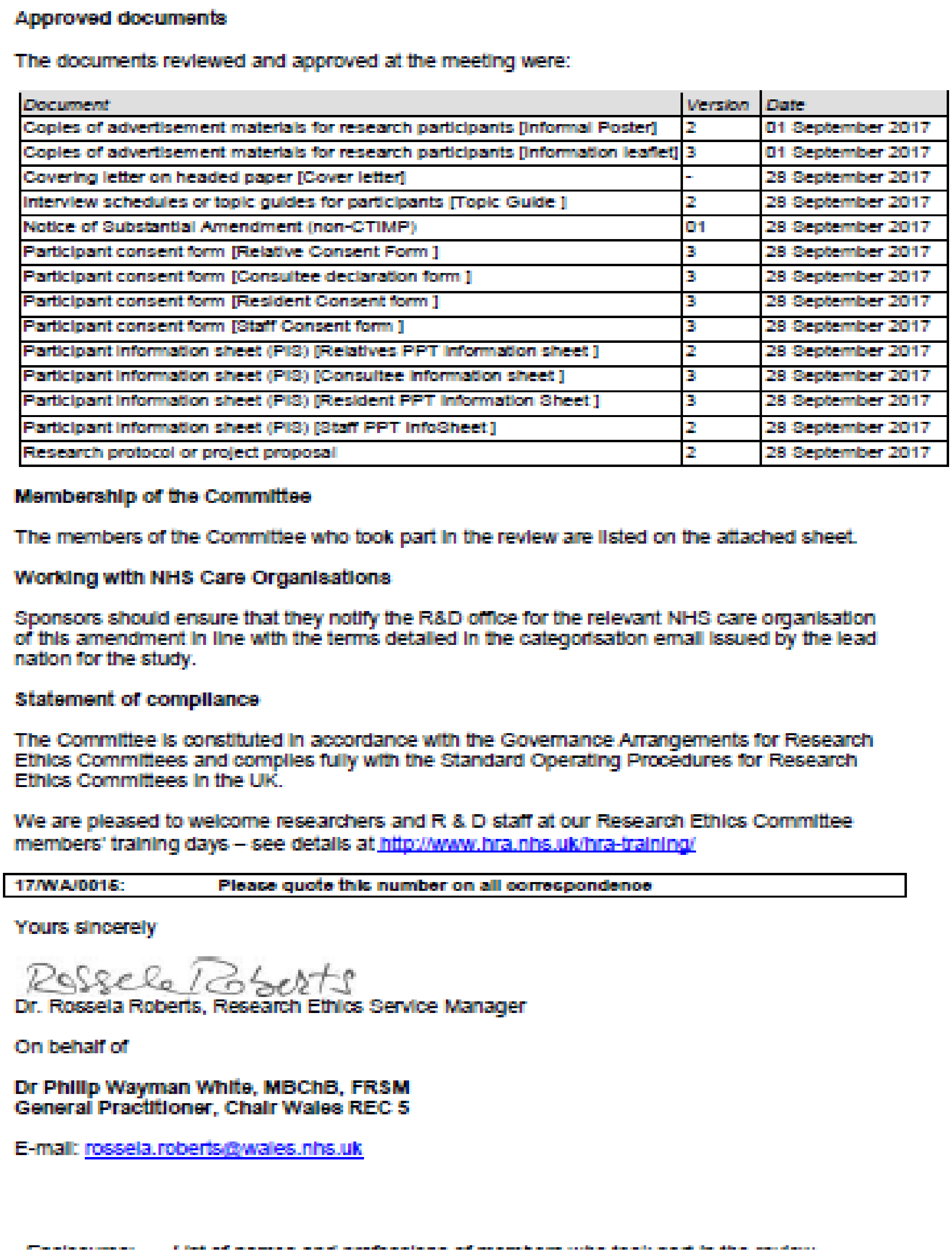
Study title:	**The quality of life of people living with advanced dementia: A pilot study**
REC reference:	**17/WA/0015**
Amendment number:	**01**
Amendment date:	**28 September 2017**
IRAS project ID:	**220298**

The above amendment was reviewed at the meeting of the Sub-Committee held on 20 November 2017 in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee noted the amendment proposes changes to the study time line, the addition of new research sites and additional quantitative measures to explore carers well-being - as well as plans to disseminate finding on how to best to safeguard staff wellbeing.



Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Informal Poster]	2	01 September 2017
Copies of advertisement materials for research participants [Information leaflet]	3	01 September 2017
Covering letter on headed paper [Cover letter]	-	28 September 2017
Interview schedules or topic guides for participants [Topic Guide]	2	28 September 2017
Notice of Substantial Amendment (non-CTIMP)	01	28 September 2017
Participant consent form [Relative Consent Form]	3	28 September 2017
Participant consent form [Consultee declaration form]	3	28 September 2017
Participant consent form [Resident Consent form]	3	28 September 2017
Participant consent form [Staff Consent form]	3	28 September 2017
Participant information sheet (PIS) [Relatives PPT information sheet]	2	28 September 2017
Participant information sheet (PIS) [Consultee information sheet]	3	28 September 2017
Participant information sheet (PIS) [Resident PPT information Sheet]	3	28 September 2017
Participant information sheet (PIS) [Staff PPT InfoSheet]	2	28 September 2017
Research protocol or project proposal	2	28 September 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/WA/0016:	**Please quote this number on all correspondence**

Yours sincerely

Rossela Roberts

Dr. Rossela Roberts, Research Ethics Service Manager

On behalf of

Dr Philip Wayman White, MBChB, FRSM
General Practitioner, Chair Wales REC 5

E-mail: rossela.roberts@wales.nhs.uk

Appendix P: Informal Poster

Version 2 1/9/17

Developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

Have your voice heard

How can we help all residents live well?

How can we help residents live well when they may be unable to communicate their wishes?

We are asking **you** as residents, relatives and care staff members to be a part of this project and have the opportunity to have YOUR voice heard

Sian Hughes will be in the home regularly and is happy to chat with you about the project. If you would like to contact her please do not hesitate to get in touch,

Email: psu34d@bangor.ac.uk

Telephone: 01248 388338

Or write to Sian Hughes, Ardudwy Normal Site, Bangor University, Bangor, Gwynedd, LL57 2PZ

If you have any further queries, please contact the care home manager

Appendix Q: Interview Topic Guide

Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

Interview topic guide

Introduction

OK, before we begin the interview itself, I'd like to confirm that you have read and signed the informed consent form, that you understand that your participation in this study is entirely voluntary, that you may refuse to answer any questions, and that you may withdraw from the study at any time.

- Introduction to the chief researcher and Dementia Services Development Centre (DSDC) Wales, Bangor University

- Explanation of the aims of the research project

- Explanation of confidentiality and anonymity

- Explanation of the audio recorder, length of time of the discussion and the nature of the questions, advise that they may withdraw at any time without a reason

- Check to see if they have any questions

- Check to see if they are happy to continue

Topics/Questions

- How is well-being/qol expressed in the individuals?
  What are the signs?
  - Explore

- Well-being/QOL – How it's monitored?

- If you are making a decision on the individual's behalf, **what is the reason for this? (Why?)**
- *How are you able to communicate with your relative/resident*
  - *Explore communication methods*

- How do you feel about your role? (*care staff)*

  - Explore feelings & how it effects interaction with residents

- Care planning of resident (*relatives*)
  - Explore involvement or lack of
  - Explore planning for end of life care

- How do you know when you are making a decision on this person's behalf - that this is the best decision for that individual?

- What is the assumption do you make about the individuals ability to make decisions about their daily lives

  - Explore perception
  - Explore responsiveness

- Human rights in advanced dementia/care home setting **(views)**
  - Explore how they are maintained and protected

- What are your views and experiences on Human Rights in advanced dementia in care home settings?

- Does living in a care home make a difference to living in the community?

Conclusion:

- Thank the participant and reiterate that the interview will be confidential and that any of the data will not have their names attached. Any personal identifiers will be anonymised during transcription.

- Provide
- contact details in case they want to get in touch later

Appendix R: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Resident

Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

Why have I been invited?

We are inviting you to take part in this study because you are a resident living with dementia in a care home setting.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. It is important to address how to promote and maintain quality of life, well-being and rights. The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia. Further, the project aims to explore family care satisfaction and involvement in care planning, staff well-being, and their role within the home.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What does taking part involve

If you agree to take part in this study, we will spend time over a number of days and weeks getting to know you. We will seek to gather your views of how all residents can live well, either through chatting or using communication aids. We will provide an option for you to communicate using a tool known as Talking Mats. Talking Mats allows you to communicate using a range of pictures and symbols. Observations will also be made in public areas of the home by the researcher, using an existing observational tool, AwareCare. The researcher will observe you during a usual activity that is run by the care home. Every effort will be made to ensure that there is no disruption to the activity by the researcher being present. The research team will ask your permission to look at your medical records, care home records and care plans in order to evaluate the extent to which your needs are being met.

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and to current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia and may help identify meaningful activities for people with severe dementia, which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives. Furthermore, the research outcomes may contribute to the safeguarding of care staff members' well-being and identifying ways of supporting staff within the homes.

What are the possible risks and disadvantages of taking part?

We do not consider taking part will involve any disadvantages or specific risks or that it could cause you any harm.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspect of your participation, we would ask you first to speak to one of the research team, so that we can try to address your concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd LL57 2AS. Tel: 01248 383136. E-mail huw.roberts@bangor.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. It is stored securely and without any identifying details. Any personal details are kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records. The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your health, safety or well-being. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

We will also ask your permission for us to store in anonymised form the information that we collect from you for long-term use by the research team. This would mean that the information can be shared with accredited researchers in future so that they might understand more and learn from the information we collect also. No-one would ever be able to identify you personally from the archived information.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time without giving a reason. Withdrawing from the study will not affect your care in any way. We will continue to use the information collected about you before you decided to withdraw, unless you inform us that you do not wish for us to do so.

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programme by Bangor University on behalf of the Welsh higher education sector. The project funding partner is Mark Bailey managing director at Fairways Care Ltd. The project funding partner is the Drapers. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic

Ethics Committee, Bangor University and the Wales Research Ethics 5 (Bangor) Committee.

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

Dr Huw Roberts

School Manger,

School of Healthcare sciences

Bangor

LL57 2PZ

Phone: 01248 383719

LL57 2AS

Phone: 01248 383136.

Thank you for considering taking part in this research study!

Appendix S: Participant Information Sheet

PRIFYSGOL
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PARTICIPANT INFORMATION SHEET

Relatives

Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

Why have I been invited?

We are inviting you to take part in this study because you are a relative of an individual living with dementia in a care home setting.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. It is important to address how to promote and maintain quality of life, well-being and rights. The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia. Further, the project aims to explore family care satisfaction and involvement in care planning, staff well-being, and their role within the home.

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your relative receives.

What does taking part involve?

If you agree to take part in this study, the researcher will invite you to partake in an interview which could last approximately 1 hour. This will take place at a convenient time in the care home. Before this interview the researcher will discuss with you the topics of the questions and check that you are happy to continue.

It would help the researcher to audio record interviews. Before the recorder is switched on, the researcher will ask you if you are willing for the interview to be recorded. If you do not wish for your interview to be recorded, you may still take part. Once the conversation has been typed up, the audio-recording will be deleted. Your name will not be linked to any transcripts. The research team will also ask permission to look at your relatives medical records, care home records and care plans to see how personalized care and needs are being maintained

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

You will also be asked to complete a questionnaire about your involvement in care planning and care satisfaction

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia. It is possible that the research will identify meaningful activities for people with severe dementia which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives. Furthermore, the research outcomes may contribute to the safeguarding of care staff members' well-being and identifying ways of supporting staff within the homes.

What are the possible risks and disadvantages of taking part?

We do not consider taking part will involve any disadvantages or specific risks or that it could cause you any harm.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspect of your participation, we would ask you first to speak to one of the research team, so that we can try to address your concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd LL57 2AS. Tel: 01248 383136. E-mail huw.roberts@bangor.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. It is stored securely and without any identifying details. Any personal details are kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records. The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your or your relative's health, safety or well-being. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

We will also ask your permission for us to store in anonymised form the information that we collect from you for long-term use by the research team. This would mean that the information can be shared with accredited researchers in future so that they might understand more and learn from the information we collect also. No- one would ever be able to identify you personally from the archived information.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time without giving a reason. Withdrawing from the study will not affect you in any way. We will continue to use the information collected about you before you decided to withdraw, unless you inform us that you do not wish for us to do so.

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programme by Bangor University on behalf of the Welsh higher education sector. The project funding partner is Mark Bailey managing director at Fairways Care Ltd. The project funding partner is the Drapers Company. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University and the Wales Research Ethics Committee 5 (Bangor).

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods	Dr Huw Roberts
DSDC Wales, Bangor University	School Manger,

Ardudwy, Normal Site,
Bangor
LL57 2
Phone: 01248 383719
Email: b.woods@bangor.ac.uk

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Email: huw.roberts@bangor.ac.uk

Thank you for considering taking part in this research study!

Appendix T: Participant Information Sheet

PRIFYSGOL
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PARTICIPANT INFORMATION SHEET

Staff member

Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

Why have I been invited?

We are inviting you to take part in this study because you are a staff member caring for an individual living with dementia in a care home.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. As it is important to address how to promote and maintain quality of life, well-being and rights. The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia**. Further, the project aims to explore family care satisfaction and involvement in care planning and staff well-being and their role within the home.**

Do I have to take part?

It is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not result in any implications at your place of work.

What does taking part involve?

If you agree to take part in this study, the researcher will invite you to partake in an interview which could last approximately 1 hour at a convenient time during your shift in the care home. Before this interview the researcher will discuss with you the topics of the questions and check that you are happy to continue.

It would help the researcher to audio record interviews. Before the recorder is switched on, the researcher will ask you if you are willing for the interview to be recorded. If you do not wish for your interview to be recorded, you may still take part. Once the conversation has been typed up, the audio-recording will be deleted. Your name will not be linked to any transcripts. The research team will also ask permission to look resident at medical records, care home records and care plans to see how personalized care and needs are being maintained. Additionally, the researcher will invite you to complete questionnaires in regards to your role in the care home and your well-being

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia. It is possible that the research will identify meaningful activities for people with severe dementia which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives. Furthermore, the research outcomes may contribute to the safeguarding of care staff members' well-being and identifying ways of supporting staff within the homes.

What are the possible risks and disadvantages of taking part?

We do not consider taking part will involve any disadvantages or specific risks or that it could cause you any harm.

What if something goes wrong?

If you are unhappy or dissatisfied with any aspect of your participation, we would ask you first to speak to one of the research team, so that we can try to address your concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd LL57 2AS. Tel: 01248 383136. E-mail huw.roberts@bangor.ac.uk

Will my taking part in the study be kept confidential?

All information collected about you during the course of the study will be kept strictly confidential. It is stored securely and without any identifying details. Any personal details are kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records. Information and answers that are provided during interviews will be kept confidential and will be anonymized. There will be no link to your identity and your given answers.

The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your or a resident’s health, safety or well-being. If this happens the researchers have a duty to inform an appropriate professional, such as your GP or social worker. We would make every effort to explain to you why we need to share this information before doing so.

We will also ask your permission for us to store in anonymised form the information that we collect from you for long-term use by the research team. This would mean that the information can be shared with accredited researchers in future so that they might understand more and learn from the information we collect also. No-one would ever be able to identify you personally from the archived information.

What will happen if I change my mind about taking part?

You are free to withdraw from the study at any time without giving a reason. If you wish to withdraw from the research, there will be no implications at your place of work. We will continue to use the information collected about you before you decided to withdraw, unless you inform us that you do not wish for us to do so.

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programmed by Bangor University on behalf of the Welsh higher education sector. The project funding partner is Mark Bailey managing director at Fairways Care Ltd. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University and Wales Research Ethics Committee 5 (Bangor).

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2

Phone: 01248 383719

Email: b.woods@bangor.ac.uk

Dr Huw Roberts

School Manger,

School of Healthcare sciences

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Phone: 01248 383136.

Email: huw.roberts@bangor.ac.uk

Thank you for considering taking part in this research study!

Appendix U: Nominated Consultee Information

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Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

PERSONAL / NOMINATED CONSULTEE INFORMATION SHEET

Introduction

A person with dementia is being invited to take part in a research study, but is thought to lack the capacity to give consent on his/her own behalf. We would therefore like to ask your advice regarding whether this person should participate. In particular, we would like to know what you think this person's feelings and wishes would be with regard to taking part. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide this person would have no objection to taking part, we will ask you to read and sign the consultee declaration on the last page of this information sheet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think he/she should be withdrawn.

If you decide that this person would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice. We will understand if you do not want to take on this responsibility.

Before you give advice, it is important that you understand what the research will involve for this person and why it is being done. Please take time to read the following information and discuss it with others if you wish. Ask us if there is anything that is not clear or if you require further information about this study. Take your time in deciding whether this person would wish to take part.

Thank you for reading this information sheet.

What is the purpose of this study?

The current study aims to investigate the quality of life of people with advanced dementia. It is important to address how to promote and maintain quality of life, well-being and rights. The majority of the work in this area focuses on the early stages of the disease. Although important, it is critical not to neglect needs of those most vulnerable, in the later stages of dementia. Further, the project aims to explore family care satisfaction and involvement in care planning.

Why has this person been invited?

This person has been invited as they are living with advanced dementia in a care home setting and we need people with advanced dementia to add to the current knowledge base.

Does this person have to take part?

This person does not have to take part. It is up to you to advise whether or not this person should be included. If you do decide that he/she would wish to participate, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to change your advice at any time without giving a reason. A decision to withdraw this person at any time, or advice that he/she should not to take part, will not affect the standard of care that he/she receives.

What will this person have to do?

If you agree for this person to take part in this study, we will spend time over a number of days and weeks getting to know them. We will seek to gather his/her views of how all residents can live well, either through chatting or using communication aids. We will provide an option for you to communicate using a tool known as Talking Mats. Talking Mats allows you to communicate using a range of pictures and symbols. Observations will also be made in public areas of the home by the researcher, using an existing observational tool, AwareCare. The researcher will observe this person during a usual activity that is run by the care home. Every effort will be made to ensure that there is no disruption to the activity by the researcher being present. The research team will ask your permission to look at the residents' medical records, care home records and care plans in order evaluate the extent to which their needs are being met.

Please be aware that as part of this research project observations will be carried out in public areas of the care home during everyday activity. The researcher will always inform residents, relatives and staff when about to undertake an observation session, so people may opt out if they wish.

What are the possible disadvantages and risks of taking part?

No risk to participants is anticipated during this research study and we would not expect any harmful effects from observations and interviews with participants. Should any of the participants feel uncomfortable or distressed they will be supported by the research team. Additionally, participants will be made aware that they are free to withdraw from participation at any time.

What are the possible benefits to taking part?

The results of the research aim to contribute to better care, quality of life and well-being for people living with advanced dementia and current knowledge of human rights in advanced dementia in care home settings. The findings may contribute to the development of better ways of maintaining well-being to improve the quality of life among care home residents with advanced dementia and may help identify meaningful activities for people with severe dementia, which is a challenge for care homes. Additionally, investigating rights and choices where verbal communication is limited or lost will possibly identify other ways of communicating with the resident and opportunities for the individual to make choices about their daily lives. Further, the project aims to explore family care satisfaction and involvement in care planning and staff well-being and their role within the home.

Will this person's taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about him/her will be handled in confidence. All data is stored without any identifying details under secure conditions. The only people who will have access to view identifiable data is the researcher and supervisor. Confidentiality would only ever be broken if there was a concern that the person might be at risk of harm.

What will happen if this person doesn't want to continue with the study?

He/she will be free to withdraw from the study at any time, without giving a reason. Withdrawing from the study will not affect the standard of care he/she receives.

What if there is a problem?

If you are unhappy or dissatisfied about any aspect of this person's participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. You can talk to the researcher or to Professor Bob Woods (see contact details below). If you are not satisfied with our response, you can make a complaint to Dr Huw Roberts, School Manager, School of Healthcare Sciences, Bangor University, Bangor, Gwynedd. LL57 2AS. Tel: 01248 383136. Email: huw.roberts@bangor.ac.uk

Who is organising the research?

The research is funded by the Knowledge Economy Skills Scholarship a major convergence programme by Bangor University on behalf of the Welsh higher education sector. The project funding partner is the Drapers. Professor Bob Woods is the Principal Investigator.

Who has reviewed this study?

This research project is reviewed by an independent group of people, called a research ethics committee, to protect patient safety, rights, well-being and dignity. This study has been reviewed and given a favorable opinion by the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University and the Wales Research Ethics Committee 5 (Bangor).

What will happen to the results of the research?

The results of this project will be presented at conferences, published in scientific journals and information will be provided for health care professionals and policy-makers. Participants will be kept informed about the progress of the project and results of the research periodically through newsletters.

Who can I contact for further information?

For further information about this research, please contact:

Sian Hughes

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Telephone: 01248 388338

Email: psu34d@bangor.ac.uk

If you have any concerns or complaints about anything to do with this study, please contact:

Professor Bob Woods

DSDC Wales, Bangor University

Ardudwy, Normal Site,

Bangor

LL57 2PZ

Phone: 01248 383719

Email: b.woods@bangor.ac.uk

Dr Huw Roberts

School Manger,

School of Healthcare sciences

Bangor

LL57 2AS

Phone: 01248 383136.

Email :huw.roberts@bangor.ac.uk

Thank you for considering this information!

Appendix V: Participant Consent Form

PRIFYSGOL
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Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

PARTICIPANT CONSENT FORM

Resident

Please initial boxes for all statements you agree to

1. I confirm that I have read and understand the information sheet (Version 3) for the above study. I have had the opportunity to consider the information and ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my care or legal rights in any way. ☐

3. I agree that if I withdraw from the study that the research team may continue to use information that I had previously provided. ☐

4. I understand that my medical and care home records and individual care plan may be looked at by members of the research team or by individuals from regulatory authorities where it is relevant to my taking part in this research. I give my permission for my medical and care home records and care plan to be accessed in this way. ☐

5. I understand that all information given by me or about me will be treated as confidential by the research team. I understand that information provided by me or about me will only be used for research purposes and my personal details will be treated with the strictest confidence. ☐

6. I understand that all information given by me or about me will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

7. I understand that if the research team observe anything that causes any serious concern about my health, safety or well-being, they have a duty to inform an appropriate professional. ☐

8. I understand that the researchers will be making observations during my daily routines and activities within public areas of the care home ☐

9. I agree to take part in the above study. ☐

Name of Participant Date Signature

....

Researcher Date Signature

....

OFFICE USE ONLY :

Participant Identification number:

Appendix W: Participant Consent Form

Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

PARTICIPANT CONSENT FORM

Relatives

Please initial boxes for all statements you agree to

1. I confirm that I have read and understand the information sheet (Version 3) for the above study. I have had the opportunity to consider the information and ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my relatives care in any way ☐

3. I agree that if I withdraw from the study that the research team may continue to use information that I had previously provided. ☐

4. I understand that all information given by me or about me will be treated as confidential by the research team. I understand that information provided by me or about me will only be used for research purposes and my personal details will be treated with the strictest confidence. ☐

5. I understand that all information given by me or about me will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

6. I understand that if the research team observe anything that causes any serious concern about my or my relative’s health, safety or well-being or concerns regarding my relative, they have a duty to inform an appropriate professional. ☐

7. I understand that some interviews will be audio recorded for later analysis purposes only. Where these interviews are transcribed, any personal details will be anonymised so that I cannot be identified. I agree to my interview being audio recorded. ☐

8. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
....	....	....

Researcher Date Signature

....

OFFICE USE ONLY:

Participant Identification number: ☐☐☐☐

Appendix X: Participant Consent Form

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Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

PARTICIPANT CONSENT FORM

Staff Members

Please initial boxes for all statements you agree to

10. I confirm that I have read and understand the information sheet (Version 3) for the above study. I have had the opportunity to consider the information and ask questions. ☐

11. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect employment at the home in any way ☐

12. I agree that if I withdraw from the study that the research team may continue to use information that I had previously provided. ☐

13. I understand that all information given by me or about me will be treated as confidential by the research team. I understand that information provided by me or about me will only be used for research purposes and my personal details will be treated with the strictest confidence. ☐

14. I understand that all information given by me or about me will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

15. I understand that if the research team observe anything that causes any serious concern about my health, safety or well-being, or concerns regarding residents, they have a duty to inform an appropriate professional. ☐

16. I understand that some interviews will be audio recorded for later analysis purposes only. Where these interviews are transcribed, any personal details will be anonymised so that I cannot be identified. I agree to my interview being audio recorded. ☐

17. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
....	....	....
Researcher	Date	Signature
....	....	....

OFFICE USE ONLY:

Participant Identification number: ☐☐☐☐

Appendix Y: Consultee Declaration

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Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

CONSULTEE DECLARATION FORM

Please initial boxes for all statements you agree to

I ………………………………..[name of consultee] have been consulted about ………………………………....[name of potential participant]'s participation in this evaluation. I have read and understand the information sheet (Version 3) for the above study I have had the opportunity to ask questions about the study and understand what is involved. ☐

☐

1. In my opinion he/she would have no objection to taking part in the above study.
2. I understand that participation is voluntary and that I am free to request he/she is withdrawn at any time, without giving any reason. I understand that if he/she withdraws this will not affect his/her care or legal rights in any way. ☐

☐

3. I agree that if the participant is withdrawn from the study that the research team may continue to use information previously provided.

4. I understand that his/her medical and care home records and care plans may be looked at by members of the research team or individuals from regulatory authorities where it is relevant to participation in this research. ☐
   I give my permission for these individuals to have access to his/her records.

I understand that all information about the participant will be treated as confidential by the research team. I understand that information provided will only be used for research purposes and personal details will be ☐
treated with the strictest confidence.

5. I understand that all information will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

6. I understand that if the research team observe anything that causes any serious concern about this person's health, safety or well-being, they have a duty to inform an appropriate professional. ☐

7. I understand that the researchers will be making observations during daily routines and activities within public areas of the care home. In my opinion, he/she would have no objection to being observed. ☐

Name of Participant

………………………………………………………………………………

Name of Consultee Date Signature

....

Researcher Date Signature

…………………………………………………… ………………………… ………………………………

OFFICE USE ONLY:

Participant Identification number: ☐☐☐☐

Appendix Z: Participant Consent Form

PRIFYSGOL
BANGOR
UNIVERSITY

Recognising the challenge, responding to need and mapping a way forward: developing an environment to safeguard the quality of life (QOL) and wellbeing of people with advanced dementia in the care home sector

PARTICIPANT CONSENT FORM

Staff Members

Please initial boxes for all statements you agree to

1. I confirm that I have read and understand the information sheet (Version 3) for the above study. I have had the opportunity to consider the information and ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect employment at the home in any way ☐

3. I agree that if I withdraw from the study that the research team may continue to use information that I had previously provided. ☐

4. I understand that all information given by me or about me will be treated as confidential by the research team. I understand that information provided by me or about me will only be used for research purposes and my personal details will be treated with the strictest confidence. ☐

5. I understand that all information given by me or about me will be anonymised. I give my permission for this anonymised data to be shared with other researchers and to be stored in data archives so that it is accessible to other researchers in future. ☐

6. I understand that if the research team observe anything that causes any serious concern about my health, safety or well-being, or concerns regarding residents, they have a duty to inform an appropriate professional. ☐

7. I understand that some interviews will be audio recorded for later analysis purposes only. Where these interviews are transcribed, any personal details will be anonymised so that I cannot be identified. I agree to my interview being audio recorded. ☐

8. I agree to take part in the above study. ☐

Name of Participant Date Signature

....

Researcher Date Signature

....

OFFICE USE ONLY:

Participant Identification number:

Appendix AA: Project Newsletter

Research at Fairways

Project Newsletter
Project sponsor: Bangor University. Company Partner: Fairways Care & the Drapers Company
Researcher: Sian Ellen Hughes

Project News

Hello!

You may have seen my project information leaflets around and we've had a chat. However, there are many of you that I've not had the opportunity to talk too yet!

XXXXXX has been offered the exciting opportunity to take part in a research project in partnership with Bangor University. This is part of a PhD project being conducted by Sian Hughes, based at the Dementia Services Development Centre, Bangor. We are now looking to recruit participants to take part in the second phase of the project.

During the first phase, families who were able to visit the home daily took part. During my time at Fairways, I have observed the day to day running of both XXX and XXXX. Of course, whilst I’ve been at Fairways I’ve witnessed the positive work being carried out by care staff and the daily challenges that they face.

We have seen some fantastic results and gained insight into residents’ well-being and lived experiences at the care homes. Taking the project forward, we’re interested to talk to family members who do not have the opportunity to visit regularly.

Who are we looking for?

- Family members who visit regularly
- Family members who do not have the opportunity to visit regularly
- Care staff members looking after the residents

Who to contact?

You can contact the researcher **Sian Hughes** 01248 833488/psu34d@bangor.ac.uk

Also Sian will be available at the home for a chat!

Appendix BB: Partner Organisation Update

Research at Fairways

Project Newsletter
Project sponsor: Bangor University. Company Partner: Fairways Care
Researcher: Sian Ellen Hughes

FAIRWAYS Care Ltd

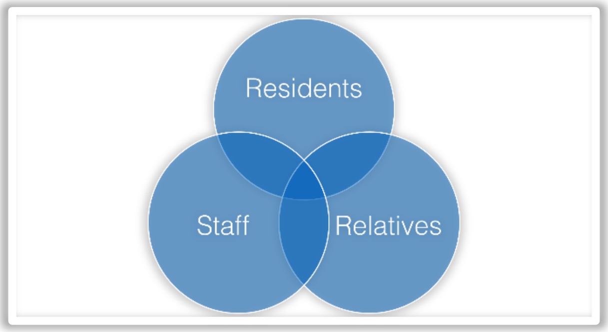
Canolfan Datblygu Gwasanaethau Dementia Cymru
Dementia Services Development Centre Wales

PRIFYSGOL BANGOR UNIVERSITY

Project update

The first year of the project is now complete and the initial results have been analysed! During this year, I’ve observed individual residents over a period of 45 hours as well as the care environment at Fairways. During my time here at Fairways, I have observed the day to day running of both XXXX and XXXX

What has been evident in both homes, is the family involvement in residents’ care provision and the wonderful friendship between families and the care staff team.



Of course, whilst I’ve been at Fairways I’ve witnessed the positive work being carried out by care staff and the daily challenges that they face. The results thus far have highlighted the importance of family involvement in care and how a collaborative effort among families and between care staff and families enable a person centred approach. Further, a great emphasis is placed on *“the girls”* and the high-quality care they provide residents. They support residents’ well-being and families, improving the journey of the care experience by adding to the support network of family members.

Each household is an individual home made up of different residents, care staff and families. *“It’s the people that make it a home, it’s not just one big home, it’s four individual homes” – relative* It has been a pleasure for me as a researcher, seeing people coming together, families joining for dinner, dish washing and drying together, supporting one another – a real community!

Benefits of family involvement in care identified during this phase of the project

- Higher satisfaction of care quality
- Care staff have better knowledge of their residents as a whole person

Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

- Collaborative care strategy between families and care staff members
- Detailed and increased care planning of the residents
- Supportive environment for residents, families and care staff
- Lower levels of distress for families visiting loved ones in care homes

- Easier transition for both residents moving into a care home setting and loved ones
- Families still feel involved in their resident's day-to-day care

UNDEB EWROPEAIDD
EUROPEAN UNION
Llywodraeth Cymru
Welsh Government
Cronfa Gymdeithasol Ewrop
European Social Fund

What's Next?

As this phase has gone well, the project has been extended for another two years, funded by the charity the Drapers Company. I'm delighted to be continuing to work with you all, residents, families and staff as well as in XXXXX and other local care homes. And last but by no means least I want to say a big thank you to you all for welcoming me into the Fairways family. Thank you all for your contribution to this project and to Fairways.

Appendix CC: Letter to absent families

Ardudwy
Normal Site
Bangor University
Gwynedd
LL57 2PZ

6th March 2018

Dear Sir/Madam,

XXXXXX care home is supporting an exciting research project in partnership with Bangor University. This research builds upon the research with families of residents in XXXXXXXXXX and XXXXXXXXXXXXX At XXXXXXXX we are hoping to talk to family members who may not have the opportunity to visit their relatives regularly. This will help us understand how best to support the well-being and needs of these residents.

We are looking to recruit participants to take part in the second phase of the project. The research also involves understanding different living environments, particularly as XXXXXXX is currently at transition, and we are keen to discuss this with you.

This is part of a research into well-being, conducted by Sian Hughes as part of her PhD student in Bangor University. We appreciate that you’re time with loved ones in the care home is precious. Therefore, we could schedule to meet you at a time which will be convenient for you. Interviews can also be on the telephone or face-to-face.

If you are happy to help us with the research, please fill in the enclosed consent form and return to us in the envelope provided. If you have any questions about the project, please do not hesitate to get in touch.

With very best wishes,

Sian Hughes

PhD student at Bangor University

Tel: 01248 388308 // email: psu34d@bangor.ac.uk.

Please leave a message and I will get back to you if I am out of the office.

Appendix DD: Example of Annotated Transcript

S*: Sian*

P*: Participant*

S: How would you say her quality of life, her well-being, how is it expressed?

P: How does she express it?

S: Yeah

P: Well one she nods, because she can't communicate, the way she communicates is by hand holding, and she holds hands very very tight. So not a lot, she smiles. You can see she is quite animated with us, and she chunters you know. But she communicates really with hands [Communication methods]

S: So her well-being, is it something that you can see?

P: Yeah you can see she's well because she's awake for a start and she's more animated in her face and her facial expressions, she makes different facial expressions. There's a lot of frowning these days sometimes I get a little bit concerned. I just wonder, I hope that she's not in any pain because she's got other health issues as well. [body language, communication]

S: So how would you say her well-being is monitored here?

P: How would I say it's monitored here, the staff are very good, the caring staff are excellent, and obviously she's been cared for very well. I don't feel that I'm kept informed [standard of care, care staff] [relative involvement]

S: Yeah I understand

P: Yeah, I don't get informed. Changes, mam's gone from having solids to a liquidised diet and I wasn't told, I just had to find out for myself, so you know it's… and the same with the drinks [relative involvement]

S: That must be difficult for you

P: Yeah, one time, I came in and as I was walking down the corridor to her room, they said she wasn't well she's in her room, she's in bed. I could hear her breathing and wheezing down the corridor and nobody had let me know. Oh you're mam's had a chest infection, when I asked them what it was. I don't feel as if I matter It is very distressing sometimes and there's sometimes you think, well you just take things in your stride and others.. [family involvement]

S: I understand, that must be difficult for you.

S: How would you say that you communicate with your mum?

P: Oh I talk to mam constantly, I sit and talk and tell her what's gone on, ask how she is and tell her about the grankids, what we've been doing on the weekend. So I talk.. Non-stop and sometimes I get a response, sometimes I don't [responses, communication]

S: How does she respond?

P: I'm holding her hand and she, you can feel her tightening and especially if you're taking your hand away. I try and have the same conversation I used to have with her years ago as, as she was. I try showing her photographs you know modern technology on the mobile phone but of course she's got catorax as well so I'm unsure whether she can see. She seems to see something, because you know, she'll start (gestures pointing) so you know I hope that she is seeing something [interaction, form of activity, responses]

S: I think we've already touched on this but, how do you feel about you're involvement in her care planning here or lack of. Do you feel that you have any involvement in her care planning?

P: Once a year I'm called over what is it

S: Reviews?

P: We used to have meetings here, erm.. but I haven't been to the meeting, I don't know whether they've had meetings for residents, for families of residents, I don't know whether they have. If they have, I've been missing them. We couldn't make all of them, but they were about once a month. You know or once every three, 4 months, but it was quite nice to know. But they do let us know if there's any changes, they usually send out a letter but they do have my email address [involvement]

S: But do you feel you have involvement in her care planning?

P: Well, not really no, I'm not quite sure whether that's what I would say. I just don't feel involved, but I'm here and I can make some decisions for mam [involvement]

S: Yes and I was just about to ask you, how do you, you know how do you make decisions within her best interest?

P: How do I make decisions, well obviously if I've been advised, or if they've spoken to me, which isn't very often. There has been GP's before and there's a care plan in place and there's end of life, that's been put in place, so we have had involvement, but I don't feel involved in the day to day. Nobody says, is there anything you would like to have a chat about. There is a box over there for suggestions but that's not the same is it [informed, involvement, care planning]

P: I don't come very often, I come once a week, depending on whether I've got the car. I try and get over once a week [visiting]

S: Yeah it can be difficult can't it

P: Yeah

S: How would you say her human rights are kept and maintained here?

P: Well ehm.. I think and it's not just for mam but I do think that their dignity sometimes isn't respected and I think you know, I have in the past heard staff chatting about them and you could hear it inappropriate [dignity]

S: Yes I think it's very important,

P: And we don't know what they know and talking about the person as if they're not in the room little things like that [dignity, awareness, privacy]

S: Yeah, so you would say the smaller things really

P: And dignity for mam, you know sometimes her skirts raised, well they could just put her blanket over it, you know just a little thing like that [dignity]

S: Yeah, so how do you view human rights for people living with advanced dementia in care homes overall?

P: Overall? I think well, what can you say about them really? I think human rights, without things like dignity… I assume most people have care plans put in place. You know their human rights as far as, you know they're stuck in here, they don't go out [dignity, activity]

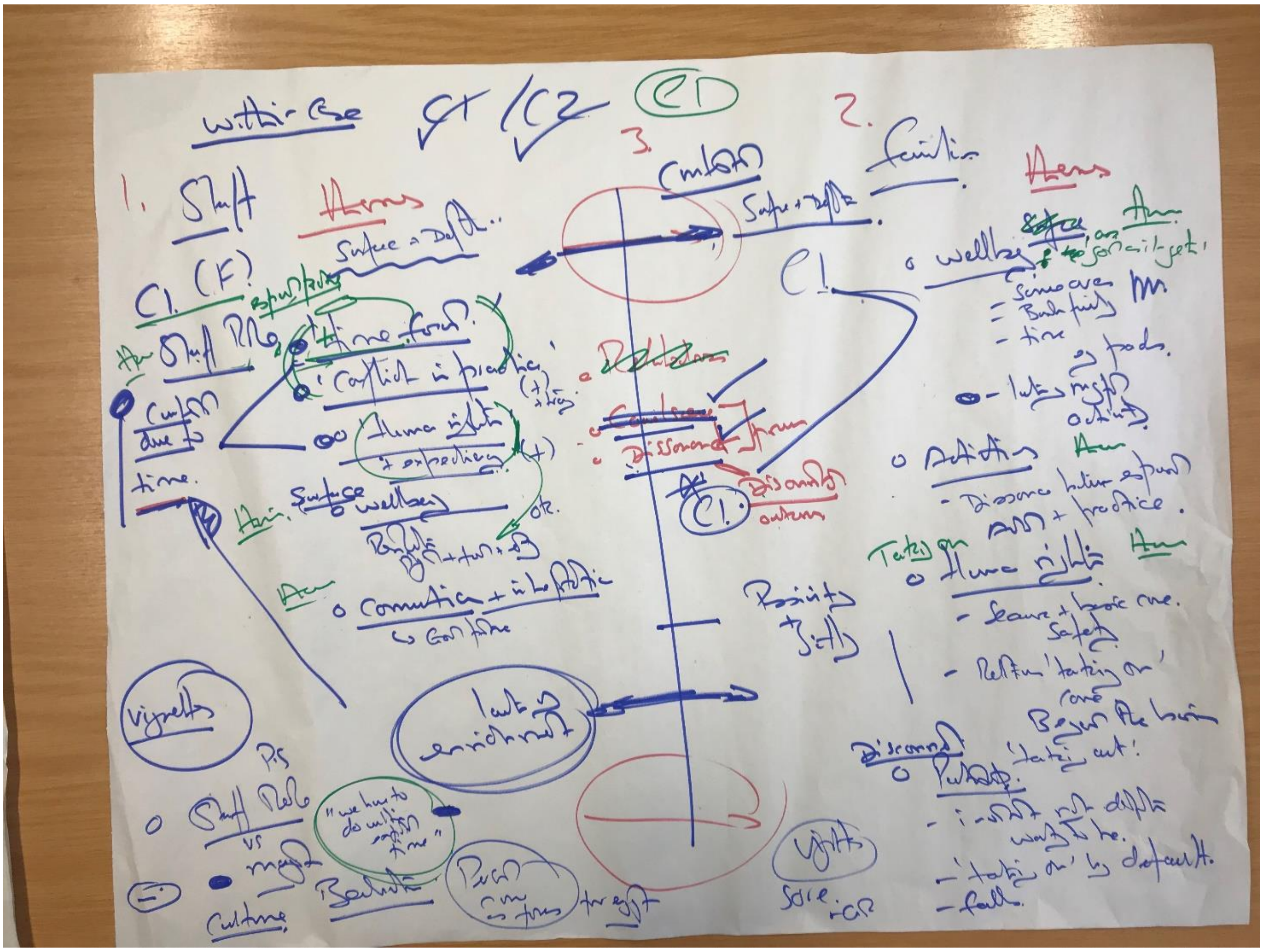
S: So do you think that their human rights are different living in the home, as oppose to living in the community?

P: Yeah it would be nice now, they're opening up the bottom a bit (referring to the garden) aren't they so they could be able to get out, even if they are in their chairs, hopefully they can be wheeled out [outside, activity]

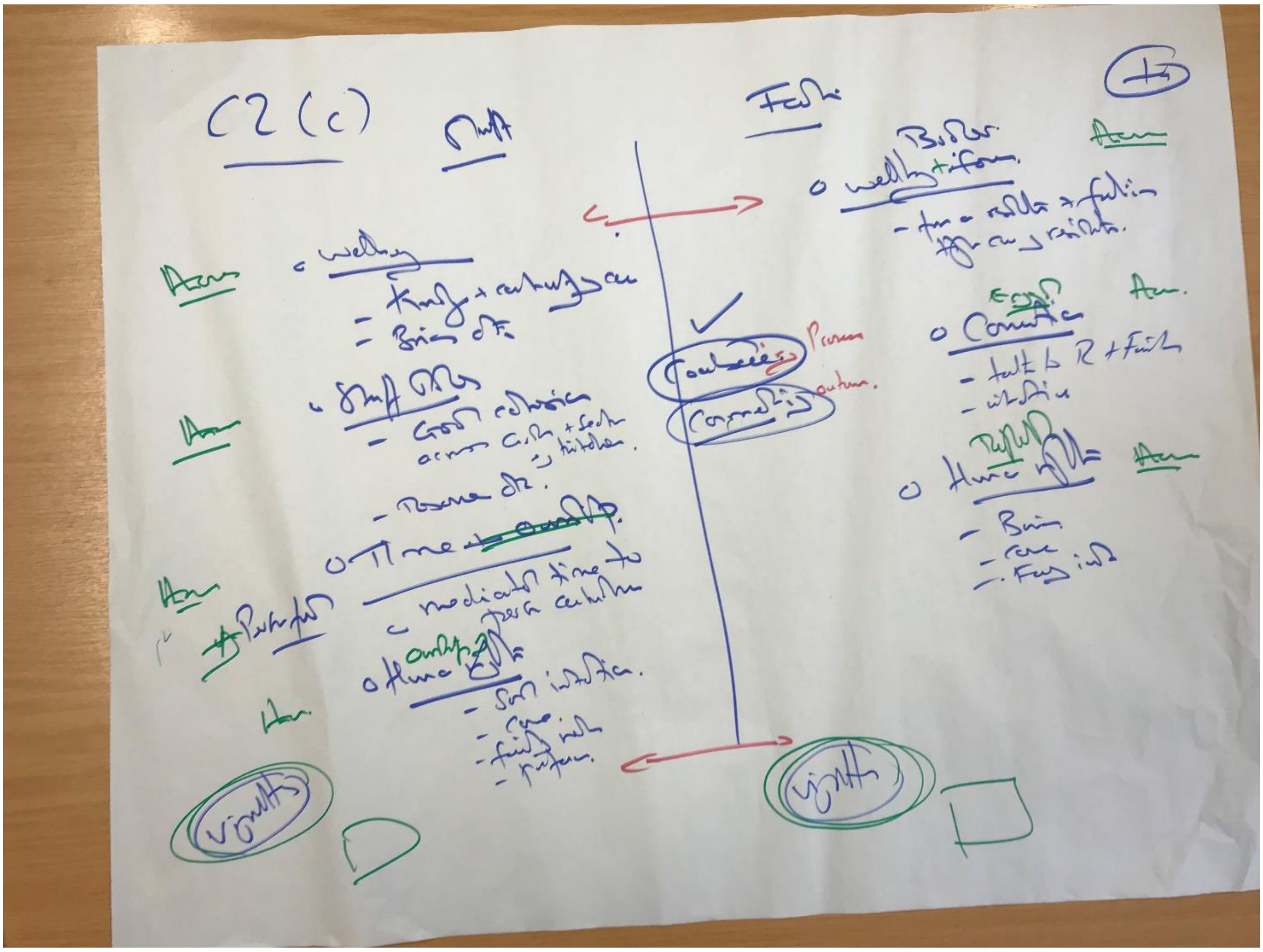
S: That would be lovely

Appendix EE: Chapter 6 Analysis Process

Care Home 1



Care Home 2


C2 (c)
Staff
Family
kitchen
Time
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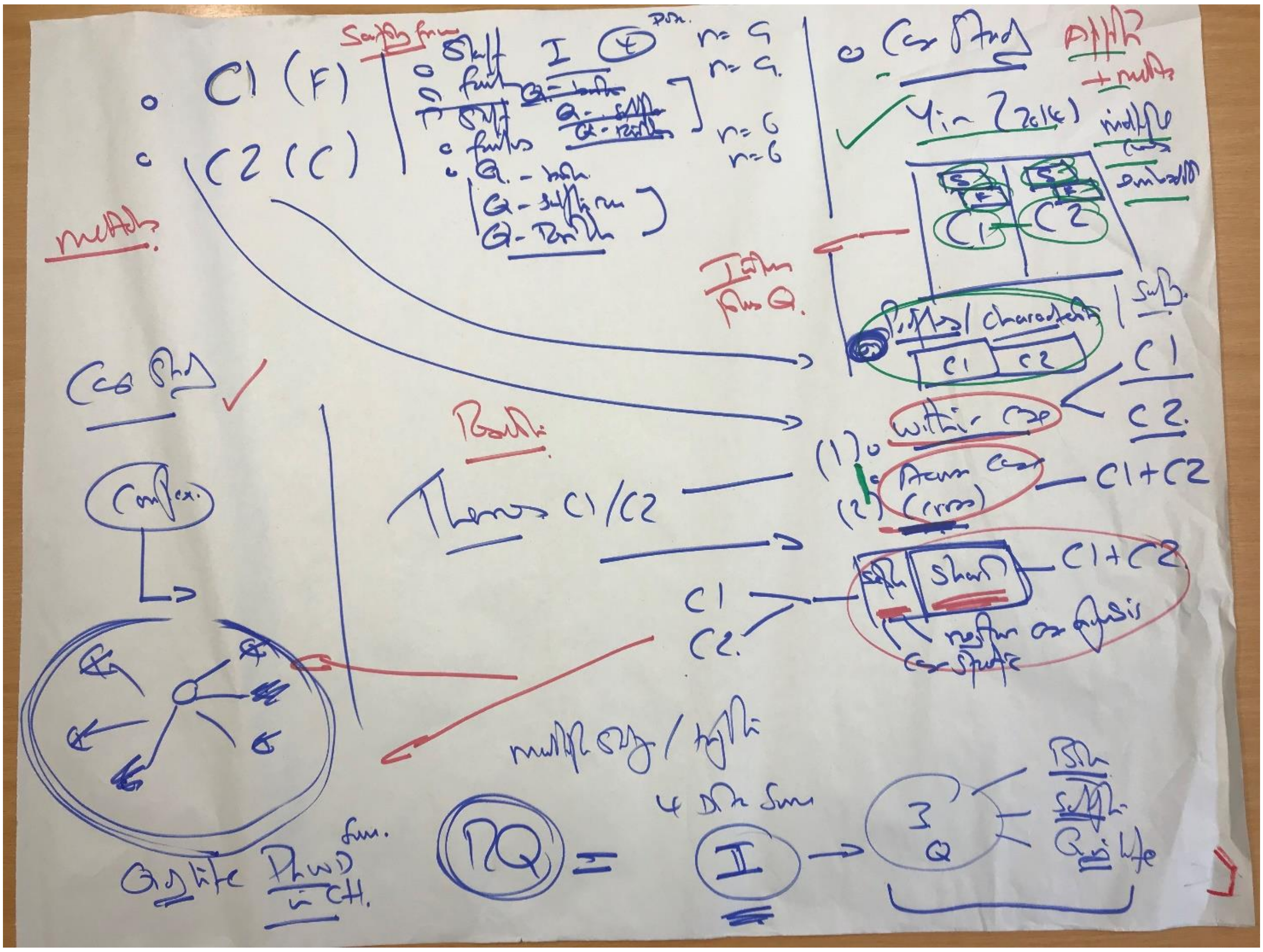
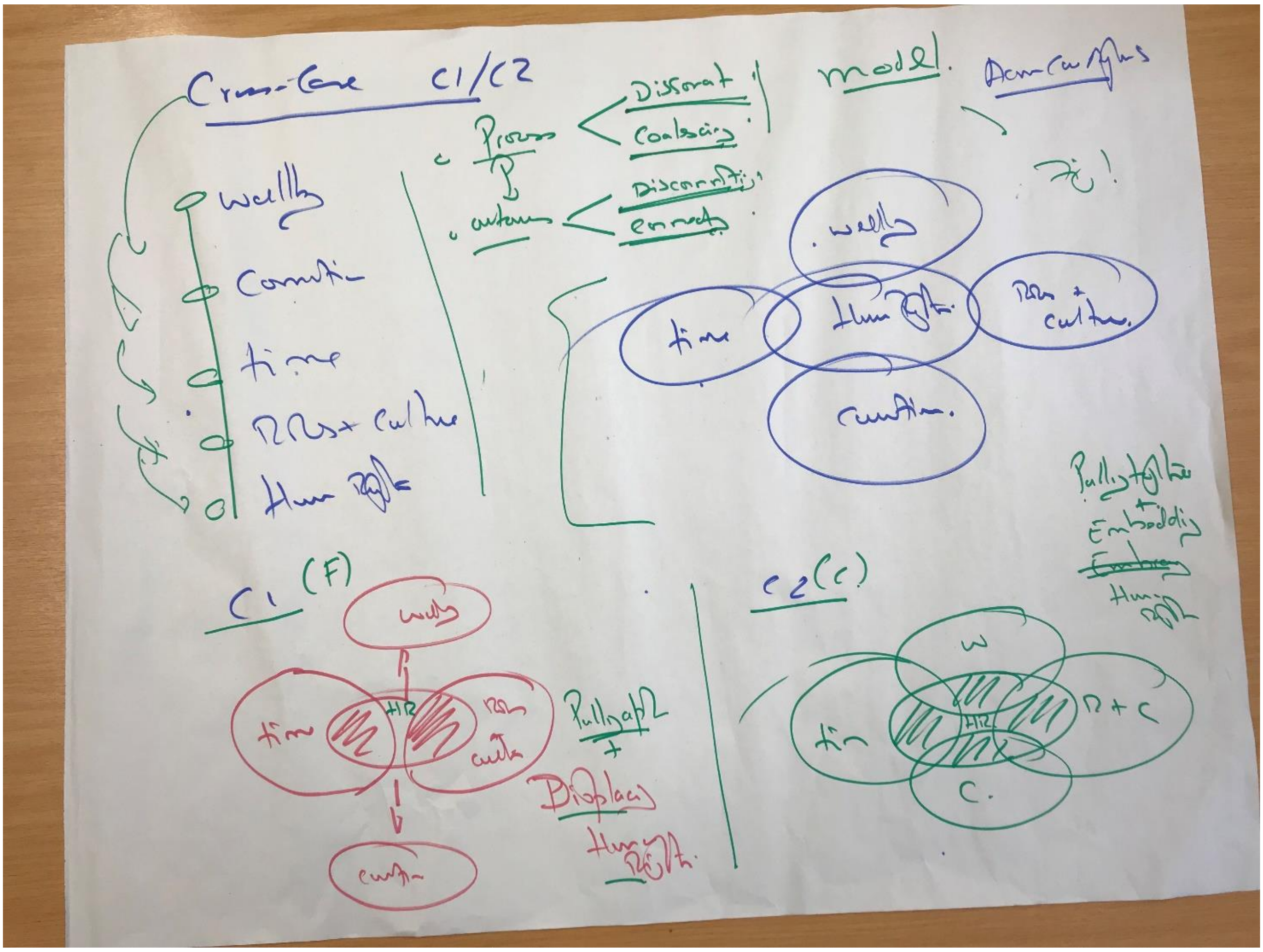
Vignettes
Vignettes

Care Home 1 and Care Home 2 as Cases



Care Home 1 and Care Home 2 as Cases



Appendix FF: Reporting Serious Adverse Events

Reporting
Serious Adverse Events (SAEs)
in
The quality of life of people with advanced dementia: A pilot study

Contents

1. Serious Adverse Events (SAE) and Suspected Abuse or Neglect Protocol

Reporting Serious Adverse Events in

Instructions

1. Upon becoming aware of an adverse event involving a participant or carer, determine whether it is "serious" by examining the criteria below.

A Serious Adverse Event (SAE) is an untoward occurrence experienced by either a participant or carer which:

a) results in death;
b) is life-threatening;
c) requires hospitalisation or prolongation of existing hospitalisation;
d) results in persistent or significant disability or incapacity;
e) * results in action taken due to suspected abuse or neglect of a participant/s, e.g. action undertaken relating to the protection of vulnerable adults (POVA);
f) is otherwise considered medically significant by the researcher and Principal Investigator.

- As this is an educational research project, rather than a trial of an intervention, there is no expectation that the chief researcher will pro-actively seek information regarding SAEs outside the context of the assessments undertaken as part of the project.

- If the researcher see's anything that would be considered abuse or neglect they would report to the care home manager in the first instance and follow the care homes usual procedures for reporting.

- The researcher would also report to the academic advisory team and the project partner (director of Fairways). If the supervisory team and project partner decide this matter should be escalated further you will follow the advice and comply with the usual reporting regulations.

* Reporting Suspected Abuse or Neglect

If the researcher suspects abuse or neglect of a participant or carer, through either allegation or observation during assessment interviews the following procedure should be followed.

What is abuse or neglect?

Abuse is when a person has caused harm, or may be likely to cause harm through neglect or subsequent abuse, to the physical, sexual, emotional/psychological, financial or material well-being of another person.

The abuser may be anyone, this includes a relative, friend or neighbor, a health or social care professional, volunteer, visitor or someone who has befriended the vulnerable person.

Preparation

The chief researcher has familiarized themselves with this document and additionally the usual care home guidelines and protocols relating to suspected abuse or neglect prior to field work.

In the event of suspected abuse or neglect

1. The researcher suspecting the abuse should inform the vulnerable adult of the need to share the information with the supervisory team and where relevant the referring team (for example, their clinical team, GP, Social Services etc). Where possible, the researcher should highlight that the participant agreed through their informed consent sheet for the researcher to report any concerns in their best interests.

2. If the vulnerable adult lacks mental capacity, then the immediate carer as their personal consultee should also be informed, unless they are the alleged perpetrator.

3. The chief researcher should record accurately the events and facts or suspicions (dated and clearly signed).

If the vulnerable adult is in immediate danger

1. Immediate steps must be taken to protect the vulnerable adult
2. In life-threatening situations, the police must be contacted immediately.
3. The care home director must be contacted and informed as soon as possible.
4. The referrer (Clinical team, GP, Social Services etc) must be contacted and informed as soon as possible.
5. The supervisory team and responsible clinical team will be responsible for any further action. This will include liaising with the social services department or relevant body who determine whether a strategy / multi-agency meeting is required and ensuring that the relevant department's Protection of Vulnerable Adults procedure is followed. The research team will cooperate fully and completely with any required investigations.

If the vulnerable adult is NOT in immediate danger:

1. The care home manager and director must be contacted and informed as soon as possible.
2. The referrer (Clinical team, GP, Social Services etc) must be contacted and informed as soon as possible.
3. The local supervisory team will be responsible for any further action. This will include liasing with the social services department or relevant body who determine whether a strategy / multi-agency meeting is required and ensuring that the relevant department's Protection of Vulnerable Adults procedure is followed. The research team will cooperate fully and completely with any required investigations.