Swansea University

‘Tea for two generations’ An Intergenerational psychosocial intervention for people with dementia living in care homes

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SUMMARY

Intergenerational practice has been found to enhance the wellbeing of people living with dementia, and raise awareness of dementia amongst younger generations in several countries globally. The need for intergenerational interventions is recognised in Welsh policy, however, there is currently a limited evidence base for their potential. The aim of this study was to develop, pilot and evaluate an intergenerational intervention, linking university students with care home residents living with dementia. The intervention aimed to enhance the wellbeing of people living with dementia, who may be at risk of social isolation, and raise awareness of dementia among university students, who may form part of the social care workforce in the future. The intervention involved shared activities based on preparing and sharing food, a meaningful activity that is sometimes lacking in care homes in Wales. The intervention was designed to provide relationship, collaboration, comfort, and equality to participants, which form the basis of person-centred care and contact theory. A pragmatic mixed methods research design was adopted, underpinned by the principles of an experimental framework. Data was gathered from participants and care home staff using Dementia Care Mapping, activity feedback sheets, questionnaires and focus groups. In sum, the thesis found that the intervention generally enhanced the mood and engagement of residents living with dementia, and the attitude of students towards dementia. The study provides additional nuanced insights that similar studies have not provided. The findings of this thesis highlighted a need for attachment to people outside of the environment in which they live, amongst *plwd* in the care home context. IG Interventions delivered in care homes provide the potential to meet this need. Feedback from care staff indicated that the intervention was suitable for a care home environment, and that observing *plwd* completing the activities prompted them to consider additional opportunities for residents to become engaged in preparing their own food. This study indicated that preparing and sharing food provides a meaningful basis for IG interventions, and that the benefits of IG interventions reported in other countries can be realised in Wales.

DECLARATION AND STATEMENTS

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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TABLE OF CONTENTS

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LIST OF ABBREVIATIONS

Abbreviation	Meaning
BCC	Behaviour Category Code
BPS	Biopsychosocial
DCM	Dementia Care Mapping
IG	Intergenerational
IP	Intergenerational Practice
ME	Mood and Engagement
MSP	Malignant Social Psychology
OPCW	Older People's Commissioner for Wales
O/T	Occupational Therapist
Plwd	People Living with Dementia
PPW	Positive Person Work
RO	Resident Only
TA	Thematic Analysis
WIB	Well, /Ill being

LIST OF FIGURES

LIST OF TABLES

1 CHAPTER 1: INTRODUCTION

This chapter provides a brief overview of the thesis. The rationale for the research and the broad research objectives will be discussed and followed with an outline of the methodological and theoretical approaches which underpin the research, and will be discussed in more depth in subsequent chapters. A summary of the subsequent chapters of this thesis will complete the chapter.

RESEARCH AIMS AND RATIONALE

This thesis aimed to design, pilot, and evaluate an intergenerational (IG) intervention, which facilitated in-person contact with university students and people living with mild to moderate dementia (*plwd*) who reside within a care home. The intervention aimed to offer *plwd* meaningful activity, and engagement with the outside world whilst improving the knowledge and attitudes of the students towards people living with dementia. The intervention sits within a broader field of intergenerational practice (IP) which aims to improve relationships between generations by providing opportunities for contact, interaction and mutually beneficial experiences (Phillips et al., 2010).

The research has evolved in a context of growing numbers of people living with dementia; a recognition of the risks of social isolation and distress that can befall them, notably through a lack of understanding, awareness and misconceptions held by others about the condition; and an emerging understanding that contact with other generations may play a key role in helping to address these risks.

Current estimates suggest that there are 35.6 million people worldwide living with dementia with numbers of people affected predicted to rise to over 115 million by 2050 (Prince et al., 2014). In the UK it is estimated that 850,000 people are currently affected by dementia which represents 1 in 79 people, 1 in 14 of those people are aged over 65. Numbers of people affected in the UK are predicted to increase by 35% to 1 million by 2025 and 146% to 2 million by 2050 (Prince et al., 2014). The prevalence rate of dementia in Wales is slightly higher than UK estimates with 1 in 71 people affected. Approximately 43,500 are living with the condition; 41,273 people over 65 (Prince et al., 2014). Figures in Wales are expected to increase by 31% by 2021, and 44% in some rural areas (Welsh Government, 2011).

The World Health Organisation (WHO, 2017) cites dementia as a worldwide public health priority. In 2017 they developed a global dementia action plan which aims to improve the lives of *plwd* and their carers whilst minimising the effect of dementia on communities, and countries. The WHO called on their member countries to develop new dementia plans, or strengthen existing ones (WHO, 2018). In the UK the Prime Minister launched a dementia challenge in 2012 which was subsequently developed (Department of Health, 2015), and reviewed and updated (Department of Health and Social Care, 2019). The Welsh Dementia Action Plan was introduced in Wales during 2018 (Welsh Government, 2018). A number of key themes are included in the action plans. Of particular relevance to this thesis is a commitment to raise awareness and understanding of dementia, and to provide meaningful care in care homes, which addresses the emotional and social requirements of the individual. This involves care homes engaging with the wider community and providing opportunities for residents living with dementia to enjoy social engagement and activities (Department of Health, 2015; Welsh Government, 2018; WHO, 2017).

Within the UK estimates suggest that one third of people living with dementia are living in care (Alzheimer’s Society, 2014), and that approximately 80% of residents living in long term care homes are living with dementia (Alzheimer's Society, 2013). In Wales there are currently over 23,000 older adults living in care homes (Older People’s Commissioner for Wales (OPCW), 2014). Residential settings can offer the necessary care and support for *plwd*, however there are limitations. For example, there may be fewer opportunities to interact with people outside of the home (OPCW, 2014), which has the potential to create disengagement from the outside world (Buckley & McCarthy, 2009, Cooney et al., 2009), and social isolation (Claire et al., 2008). For *plwd*, any social exclusion experienced in a residential care setting may be experienced more acutely as they experience the additional stigma of the condition (Bruce, 2004).

Regardless of the residential context in which older *plwd* may find themselves, or the policy initiatives which are beginning to emerge at both local, regional and global levels, an increase in the prevalence and numbers of those living with dementia is not necessarily accompanied by public acceptance of the condition, nor an understanding of its implications for those who live with it. As a result, there will be misconceptions about the condition, which in turn, bring risks of distress and social isolation for those affected (Alzheimer's Disease International, 2012). The Dementia Attitudes Monitor completed by Alzheimer's Research UK (Stevens et al., 2018) which analysed the interview responses of 2,361 people aged over 15 in the UK found that awareness of dementia is improving in the UK. However, 22% of respondents stated that they would 'find it hard to talk to someone with dementia' (Stevens et al., 2018, p.23); this figure rose to 27% amongst 15-24-year-olds. Younger adults were less likely to have had personal experience of dementia, and are a group which would benefit from interventions aimed at increasing awareness (Stevens et al., 2018).

As a potential way forward in facilitating understanding about the condition, and reducing stigma and social isolation experienced by *plwd* (Harris & Caporella, 2014; 2018), IP has more recently come to the fore. There is empirical evidence indicating that IP practice involving college and university students improves their knowledge of, and attitudes towards *plwd,* and is enjoyable and engaging for *plwd*. However, many of these studies were completed in the United States of America (USA) and therefore may not be directly relevant to other cultural contexts (Fruhauf et al., 2004; George et al., 2013; George et al., 2014; Lokon et al., 2012; Lokon et al., 2017; Sauer et al., 2014, Yamashita et al., 2011), with only a handful completed in the UK (Wood et al., 2016; Wood et al., 2017).

Focusing more specifically on IP involving university students and *plwd* living in care home settings, the literature review undertaken for this research found very little evidence of research or practice initiatives in the UK, and none were found that had been completed in Wales. This gap in knowledge is particularly significant, given that current and future cohorts of university students who have studies in areas relating for example to health, well-being, social care or management may well become involved in the workforce caring for *pwld*, and therefore need to be equipped to work effectively and appropriately with them (Wood et al., 2017). Furthermore, many may not have received any education relating to dementia in schools, and may have had no direct contact with *pwld* (Sabat, 2011; Stevens et al., 2018), on which to form their attitudes.

From the limited evidence available, it seems that IP can be effective in changing attitudes. One study completed by Wood et al. (2016) found that the volunteering in a care home improved students' attitudes towards dementia, and that the experience was 'powerful' for the students (Wood et al., 2016, p.246), although the study site did not involve *plwd*. Two examples of IP initiatives which were reported as beneficial for both university students and care home *plwd* have been undertaken in Bristol (Warne, 2017) and Exeter (Exeter University, 2012). At the time of submitting this thesis, formal evaluations of these project were not available and no examples of Welsh initiatives connecting university students with care homes were found in the academic or grey literature.

From a policy perspective, IP is now embedded in Wales (Welsh Assembly Government, 2003; 2008). In 2012, for example, the Welsh Local Government Association produced guidance for people planning IP, and in 2017, the Children's Commissioner for Wales and OPCW together launched a set of online resources to support communities to establish IP (Walsh, 2016). As a result, there are currently a number of Welsh IP initiatives with a focus on connections between care homes and schools which have reported improvements in the health and well-being of *plwd* (Gann, 2018), and a number involving care homes in Wales have been identified by the OPCW (2018). This is encouraging.

However, there is a paucity of research evidence evaluating the effectiveness and impact of these initiatives. Springate et al.'s (2008) review of IG literature based on research evaluations, internal project evaluations, and discussion papers in the United Kingdom identified 43 studies, including two documented accounts of IP in Wales. The report found that the evidence base was weak but that successful interventions resulted in positive outcomes for participants and communities, including increased understanding and friendship. However, if good practice is not followed negative outcomes can result. Bryer and Owen's review (2019) of Welsh IP designed to reduce loneliness/social isolation highlighted a lack of evidence in this area. The review included 11 academic publications and 16 reports published as grey literature, based on 13 case studies. Three of the 13 case studies operated in Wales, two more were UK based with some provision in Wales. However, evidence for their success is based on project self-evaluations, and anecdotal evidence.

This paucity of research evidence about the effectiveness and impact of IP, particularly in the Welsh context, is therefore clear, and has contributed towards the rationale and development of the research undertaken in this PhD. To this end, the current study brought university students into a care home to complete socially meaningful activities, centred on preparing and sharing food with *plwd.*

TEA FOR TWO GENERATIONS – IN THE CARE HOME SETTING

In the largest study to date completed on care homes in Wales, OPCW (2014) found that this environment is often lacking in meaningful activity such as making tea, baking, and gardening. Yet, research evidence suggests that preparing and sharing food is an area in which *plwd* can help 'maintain connection and memories with others' (Papachristou et al., 2013, p.568).

The research evidence supporting the choice of food as an activity for the intervention rather than others such as music or dance, and how the intervention has been informed by this evidence are elaborated fully in Chapter 2, section 4 (p21). To summarise, the acts of preparing and sharing food are both unique and universal in that they embody essential and ordinary elements of everyday life, both of which are difficult to recreate in a residential setting.

Consuming food is essential to human survival, and eating together is an activity that everyone is familiar with and which represents part of the fabric and ordinariness of life. As such it has the potential to act as a channel for communication, integration and self-expression, in addition to its nutritional value. The same cannot be said of other activities which have already been used in other IG interventions. Furthermore, an emphasis on enabling ordinariness is important as it has the potential to change the experience of living in a care home by transforming the identity of an individual from "resident" to someone whose life is embedded in the ordinariness of life at home. Gjernes and Måseide (2020, p1777) found that involving residents living with dementia in a Norwegian care home in 'common activities that they enjoyed doing', or being ordinary, played an essential part in maintaining their Qol.

To date, few IG interventions involving care home *plwd* have explored this domain. Two studies were reviewed during the production of this thesis. One completed in Taiwan found that a cooking intervention involving reminiscence therapy improved the mini-mental state examination (MMSE) scores and reduced rates of depression amongst *plwd* (Huang et al., 2009). Another USA study involving baking, reported that the affect and attitude of *plwd* increased during the intervention (McNair & Moore, 2010).

In sum, this PhD has grown from the knowledge that many older *plwd* are living in care homes in Wales, an environment that may lack social stimulation and meaningful activity, and one in which residents may experience social isolation through lack of meaningful links with their broader neighbourhood and community. There is some research evidence, but mostly from the US, to suggest that IP involving *plwd* has the potential to address these issues. There are also a number of IP initiatives which have been completed, or are in progress in Wales, but they are not as yet, supported by rigorous empirical evaluation, so their contribution to informing policy and practice is thus far, limited.

The overall aim of this thesis is therefore to fill the evidence gap about the role those IG interventions may play as a mechanism for improving the wellbeing, as outlined by Kitwood (1997) which is discussed fully in Chapter 3, of older *plwd* in a care home context, and their potential to change public perception of dementia as a “problem”.

The research objectives are:

1. Design an original IG intervention based on preparing and sharing food which is informed by the literature and practitioner knowledge and experience, and underpinned by theory
2. Evaluate the potential of the intervention to enhance the wellbeing of *plwd* using the Dementia Care Mapping (DCM) technique
3. Evaluate the potential impact of the intervention on the attitudes of students towards dementia
4. Explore the practicality of using the intervention from the perspective of care home staff involved in the research.

STAGES OF THE RESEARCH – BRIEF OVERVIEW

The thesis was completed in four phases which involved: (i) a review of the literature, (ii) a design phase; (iii) an implementation phase; (iv) an evaluation phase. The literature review informed the design of the study methodology, the intervention, and the evaluation. Four food-related activities were designed for the intervention to be completed on a one-to-one basis with *plwd* and the researcher/students over a period of a month (see Chapter 5 for more details).

A pragmatic mixed methods (MM) research design was adopted to complete the study, the rationale for adopting this methodology is discussed fully in Chapter 4. Briefly, this approach enabled the researcher to explore the experience of the intervention from the perspectives of three groups of participants; *plwd*, students, and care home staff (Creswell & Creswell, 2018), through the collection, and integration of quantitative and qualitative data (Creswell & Plano Clark, 2018). The data collection methods included; researcher observation using the DCM (Brooker & Surr, 2006) technique, participant focus groups, and self-completion student questionnaires. The quantitative and qualitative data was gathered simultaneously, with neither taking precedence as they were collected for different purposes. The quantitative data was collected to assess and explain change in the mood and engagement of *plwd* and the attitude of students, and was analysed using t-tests. The qualitative data was collected to explore factors underpinning the change (see Chapter 5 for more details) and was analysed using thematic analysis (Braun & Clarke, 2006).

The intervention was implemented and evaluated in two care homes, details of which are discussed fully in Chapter 5. The evaluation explored a number of aspects; the participant experience during the intervention, any changes reported in the ME of *plwd* across time, any changes reported in the attitudes of students, and the suitability of the intervention for a care home environment. In the first care home the intervention was completed by *plwd*, and an equal number of residents who were unaffected by dementia. In the second care home the intervention was completed by *plwd* and an equal number of university students, which acted as the experimental or treatment group. The aim of this design was to explore any changes that were experienced by *plwd*, as a result of the introduction of the IG element, the students, to the intervention.

A number of theories informed the design of the intervention and interpretation of findings. These are discussed in more detail in Chapter 3, and briefly, include the contact theory (Allport, 1954), and the theory of maintaining personhood (Kitwood, 1997).

Allport’s contact theory (1954) provides the basis for exploring whether personal contact between group members, older people with dementia and younger people, is effective in raising awareness of dementia in students, and subsequently improving their attitudes towards dementia. Research by Stevens et al. (2018) suggests that people in the student age group (under 25) are less likely than those over 25 to have personal experience of someone close to them living with dementia therefore may benefit from such interventions. Allport’s original hypothesis – the contact theory – aims to establish whether bringing two groups of people into contact with each other will improve the knowledge of the other group, and subsequently improve attitudes towards members of that group. Allport stipulates that there are four conditions that need to be met: groups should have equal status during contact, the groups should work towards shared goals, contact between the groups should be regular enough and long enough to develop true acquaintance, and contact between the groups should be in a supportive, normative environment. The intervention implemented in this thesis was designed to satisfy these four criteria. Although the contact theory (Allport, 1954) was originally created in the USA for use with interracial prejudice, Pettigrew and Tropp (2006) concluded that it can be generalised to other groups, and results indicate that bringing two groups together is effective in improving attitudes towards the other group. Allport’s contact theory has recently formed the conceptual framework for IG studies involving *plwd* (Caspi, 1984; Harris & Caporella, 2014; Teater, 2016; Jarrott & Smith, 2010).

Kitwood’s (1997) notion of person-centred care reflects a broader aim of maintaining ‘personhood’ throughout the life course for those *plwd.* He describes personhood as ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being’ (Kitwood, 1997, p.7). Personhood, he argues, can be maintained by ensuring that interactions with *plwd* are consistently positive and this premise has shaped the design of the IG intervention for this research, which aims to encourage or facilitate positive interactions between care home residents and students.

In sum, the research design and development of the intervention are innovative on two fronts. First, the intervention is based on preparing and sharing food, an activity which is rarely reported in the IG literature. Only two IG studies, completed outside of the UK, involving *plwd* in care homes and food preparation were identified from the literature review (Huang et al., 2009; McNair & Moore, 2010) at the time of the intervention design. Second, the current research involves university students, a key participant group which would benefit from interventions which focus on education and raising awareness of dementia (Stevens et al., 2018). At the time of designing the intervention very few studies involving this group have been completed and evaluated in the UK (Wood et al., 2017).

ORGANISATION OF CHAPTERS

The thesis is presented in nine chapters. This introduction has outlined the study background, presented the research aims and research questions, and highlighted the significance of the study. Chapter two outlines the context in which the study was completed. The chapter starts by describing the dementia plans and policies that are in place in Wales which underpin the nature of care that *plwd* in care homes should receive. This is followed by a review of the literature that focuses on two issues that care home residents may experience, and strategies that have been implemented to address them: social isolation and a lack of meaningful activity. The chapter is completed with a discussion on the role of IP in addressing social isolation in care homes in Wales. Chapter three reviews the academic literature which focuses on IG interventions involving older adults living with dementia in care homes globally. Key factors of successful interventions are identified and ways in which these informed the development, implementation and assessment of the evidence-based intervention are discussed. The chapter is completed with a presentation of revised study aims and questions, which include the perspective of care staff. Chapter four describes the research methodology, beginning with pragmatism as a paradigm. This is followed by discussion on the use of MM within research, and within this thesis. An explanation and a rationale for the study design precedes a critical appraisal of the research methods adopted for the research, and a rationale for their inclusion. The chapter concludes with a discussion of the ethical considerations, which require addressing in research in care homes involving *plwd*, and how they were addressed in this thesis. Chapter five describes the implementation process which was completed to deliver the intervention, gather data and complete the analyses. The chapter starts by describing details of the research sites and study participants, then presents discussions on key research activity completed, and the recruitment process undertaken to appoint the research team, care homes, and participants. The process adopted to gather, integrate, and analyse the data completes the chapter

Chapters six, seven, and eight present the findings. Chapter six presents the analyses of DCM data. The first section presents the eight maps which were completed during the interventions. The second section presents the findings which were based on the experimental framework; in this section comparisons are drawn between the experiences of the RO and IG groups during the activity sessions, and changes in the mood and engagement of *plwd* in the IG group across time. Chapter seven presents MM findings based on focus group data, DCM data, and data gathered with feedback sheets, which was drawn on to explore the extent to which the intervention upheld the personhood of *plwd* and how this impacted their wellbeing. Chapter eight presents the findings related to students and care home staff. Findings from student questionnaires which assessed changes in the knowledge of, and comfort with *plwd* amongst students are presented first. This is followed by the opinions of care home staff regarding the intervention and the practicality of it for a care home setting.

Chapter nine is the conclusion which discusses the strengths and limitations of the research, and proposes recommendations on how the findings can be utilised in care homes. Reflections are also included on the theories of Kitwood (1997b), Allport (1954), and Pettigrew (1998), plus the methodology, and the implementation process, which it is hoped will assist future researchers who may be planning similar research.

2 CHAPTER 2: THE STUDY CONTEXT

The aims of this chapter are twofold. Firstly, the chapter aims to outline the context in which the study was completed. Secondly, the chapter presents the findings from a review of the literature which focuses on issues which may be faced by *plwd* in a care home setting, and strategies that have been implemented to address them. Within the philosophy of pragmatism, which underpins this thesis, lies the tenet that knowledge changes throughout time and in different contexts (Denscombe, 2014; Kaushik & Walsh, 2019; Morgan, 2014). Therefore, it is essential that readers are aware of the broader Welsh national context in which the current study was completed; two residential care homes in South Wales in 2017. The chapter will start with discussion of Welsh plans and policies which underpin dementia care in Wales in general, with a focus on care homes. This is followed by a review of the literature that has provided the rationale and evidence base for the use of IG to address social isolation, and preparing and sharing food to address a lack of meaningful activity. The chapter will present findings from the literature review in care homes globally, with a focus on Wales.

2.1 THE WELSH CONTEXT

The nature of care that *plwd* receive in a care home environment is dictated by a number of factors; including dementia plans and policies in place, and contemporary conceptualisations of dementia.

2.1.1.1 Welsh dementia plans and policy

Wales currently has a dementia plan and legislation in place that are based on wellbeing, and focus on achieving outcomes for the individual that support their wellbeing. On the 14th of February, 2018 the Welsh Government launched a Dementia Action Plan which is based on 7 key themes which include raising awareness and understanding, living as well as possible, for as long as possible with dementia. The government has allocated £10 million per year to deliver this plan which focuses on a number of areas including; becoming a dementia friendly nation, people receiving person centred care, and reducing stigma. The plan will be overseen by the Welsh Government Dementia Oversight of Implementation and Impact Group (DOIIG), which is made up of *plwd* and their caregivers (Welsh Government, 2016). The government is also allocating an additional £75million over 3 years to (Welsh Government, 2018) to support the integration of health, social care and housing.

This policy plan is significant because it underpins dementia care pathways, alongside The Social Services and Well-being (Wales) Act 2014 (UK Government, 2014) and the Regulation and inspection of Social Care (Wales) Act 2016 (UK Government, 2016) which was ratified in April 2016. The principle of wellbeing is at the centre of the Act which is based on five fundamental principles: voice and control, prevention and early intervention, wellbeing and co-production, and multi-agency. The Act is supported by the Social Services Outcome Framework (Welsh Government, 2016) which applies to people who require the support of social services, and people who care for them, and the NHS outcomes framework (Welsh Government, 2019) which applies to the general population, and focuses on outcomes of services provided by Health and Social Care Services.

The Well-being of Future Generations (Wales) Act which also came into force in April 2016 is aimed at improving the social, economic, environmental and cultural well-being of Wales, and providing a good quality of life for future generations. It is based on 7 wellbeing goals including: a resilient Wales, a healthier Wales, a more equal Wales, and a Wales of cohesive communities (Welsh Government, 2015).

There are other Welsh initiatives which influence the care experienced by *plwd* living in care homes in Wales. In 2008 Wales appointed an Older People's Commissioner for Wales (OPCW) who acts as an independent voice protecting and promoting the rights of older adults living in Wales. The Commissioner has a range of legal powers which enable them to review the work of public bodies; and ensure that any recommendations are responded to, and acted upon (OPCW, 2016; Woods, 2019).

In sum, these Welsh initiatives have wellbeing at their core, and underpin the current provision of dementia care which is lifelong and extends to the care home environment.

2.1.1.2 Dementia Care and support

Dementia care is currently underpinned by the Biopsychosocial model (Engel, 1997, 1980). Dementia has been conceptualised in a number of ways throughout history, and how this ontological exercise evolved has determined what types of care are available, and how they are provided. Dementia care is now based on the biopsychosocial (bps) conception of dementia, which was proposed by Engel (1977, 1980) who acknowledged the advantages of the medical model, but argued that it should be extended to incorporate biological, social and psychological aspects of the human condition. The medical model was dominant until the 1980s however considering dementia as a wholly medical condition would mean that the only way to treat or support people living with the condition is with pharmacology. As there is currently no pharmacological cure for dementia, Sabat (2014) and Woods (1989) suggest this implies that nothing that can be done to support *plwd*.

However, the biopsychosocial model highlights ways in which *plwd* can be supported. The biomedical model has been challenged by the work of researchers such as Kitwood (1997), and Sabat (2004) through their efforts to highlight the role that social factors play in the condition (the work of Kitwood (1997) will be discussed fully in Chapter 3). The bps model of dementia was accepted by the WHO in 2002, and has formed the basis of subsequent NICE guidelines (2006, 2018), which stress the need to look at social, psychological, and medical aspects of the condition. The model is a tool to guide clinical practice (Spector & Orrell, 2010), to consider biological, psychological, and social factors when diagnosing and treating dementia as a means of ensuring that: ‘people with dementia and their families (are given) the greatest opportunity for a good life …’ (Downs et al., 2008, p154).

The growing recognition of the social aspect of dementia is accompanied by a growing recognition of the value of psychosocial interventions for dementia as an alternative to medical treatments which currently offer no cure (Moniz-Cook et al., 2011). The aims of psychosocial interventions are to improve the quality of life (QoL) and maximise the function of people with dementia. Moniz-Cook et al. (2011, p.2860) provide a more detailed description: ‘*Psychosocial interventions in dementia care encompass interventions involving interaction between people to improve psychological and /or social functioning including well-being, and cognition, interpersonal relationships and everyday functional abilities’*

Good dementia care should focus on the individual. In the UK, the Royal College of Psychiatrists (2018) considers good dementia care as lifelong and underpinned by the needs and preferences of the individual, therefore is *person centred.* Person-centred care is based on the work of Carl Rogers (1957, 1961) and was further developed by Kitwood (1997) (see Chapter 3). There is debate regarding a definition of person-centred care; Oliver and Guss (2019) suggest that the meaning of person-centred care has been lost and is now a much-overused term which professionals use to tick some requirements. However, the key factor is that the individual is treated with respect and supported to make mutual decisions about their own care (Mitchell & Agnelli, 2015).

The UK’s NICE Guidelines (2018) state that once a diagnosis has been given the person affected should also be provided with the contact details of an individual health or social care professional with responsibility for co-ordinating care. At this point a care and support plan should be developed which includes input from any informal carers. This plan needs to be reviewed periodically and permission sought from the individual to transfer this plan to different institutions if the need arises to move (hospital, care homes etc.) (NICE, 2018).

2.2 LIVING WITH DEMENTIA - THE NEED FOR RESIDENTIAL CARE

An individual living with dementia will experience a decline in cognitive abilities, which will affect their ability to complete daily activities, and their social functioning. A deterioration in cognitive abilities is a key feature of the condition and complex attention, executive function, learning and memory, language, perceptual-motor, and social cognition may be affected (American Psychiatric Association (APA), 2013; WHO, 2018). Memory loss affects the input, retention, and retrieval of new information, and the loss of previously stored information. Other impairments may involve the capacity to think, reason, and process incoming information which may make it challenging for a person living with dementia to focus on more than one stimulus at a time, and to move their attention from one stimulus to another (WHO, 1992).

As the condition progresses cognitive decline may progressively interfere with the ability of the individual to complete everyday activities independently, and to become more reliant on external support. During the ‘mild stage’ the ability to complete ‘instrumental daily activities’ such as housework and managing money become challenging, during the ‘moderate stage’ basic activities of daily living such as eating and dressing are affected, in the ‘severe stage’ the individual becomes fully dependent (APA, 2013; WHO, 1992). *Plwd* may want to stay in their own home supported by family and paid carers however this may not be possible as the condition progresses; requiring full time care may necessitate a move into residential care. Thirty-nine per cent of *plwd* over 65 are living in residential care or nursing homes (Prince et al., 2014).

2.2.1 Care home provision in Wales

Current data on care home provisions in Wales indicate that there are over 23,000 older adults living in care homes (OPCW, 2014). According to CSSIW in April 2015 there were 673 care homes in Wales, with the number of beds split equally between residential care and nursing care homes. In 2000 UK minimum standards were introduced with the Care Standards Act (2000) (UK Government, 2000). In 2014 The Care Act set the principles of personalised care and choice with the introduction of care, individual budgets and choice for service users. The focus of care shifted from ‘needs’ to ‘outcomes’ (UK Government, 2016). In 2019 new statutory guidance was issued for providers of regulated services including care home services (Welsh Government, 2019).

Residential care historically focused on physical care, however person-centred care is now the recommended model of care for *plwd* (NICE, 2018), which is reflected in the statutory guidance. If the individual does not have a care plan the care home provider must produce one which will be reviewed every 3 months. Care and support plans must outline how individual needs will be met on a daily basis, and how residents will be supported to achieve the outcomes detailed on the plan. Outcomes may be related to physical, emotional and mental wellbeing (Welsh Government, 2019). Care provided should be based on evidence-based guidance and include activities that enhance the quality of life of residents living with the condition. *Plwd* should be supported, encouraged, and enabled to participate in everyday life (Welsh Government, 2019).

In sum, the legislation, policy, guidelines, and regulatory standards discussed here have been introduced to improve the quality of care experienced by care home residents, ensuring that they are safeguarded and that their human rights are respected.

Plwd in care homes in Wales should receive personalised care which is focused on their wellbeing, and which supports outcomes which are important to them. A review of the literature follows which explored some of the issues that care home residents living with dementia may face, and strategies that have been implemented to address them.

2.3 RATIONALE FOR THE BASIS OF THE INTERVENTION: IG AND PREPARING AND SHARING FOOD- LITERATURE REVIEW

This review of the literature focused on: the use of IG practice to address social isolation, and to promote awareness of dementia, and the use of preparing and sharing food to provide meaningful activity for *plwd,* with a focus on the care home environment.

The start points for this literature review drew on the protocol developed by Dr Sarah Hillcoat-Nallétamby to secure funding for the project from the Health Management Trust (HMT). Some aspects of the research were pre-determined: the use of IG practice to address social isolation that care home residents living with dementia may experience; promoting awareness of dementia. The basis of the intervention was also pre-determined, that is preparing and sharing food. The researcher herself developed, designed and implemented the intervention and the evaluation plan around these broad features, based on the literature.

A narrative approach was adopted to reviewing the general literature to provide the researcher with a comprehensive understanding of the current state of knowledge in the topic area (Cronin et al., 2008). There are two broad types of literature review: a narrative review and a systematic review. A narrative review is broad in scope, and provides synthesis, narrative and critique of a broad selection of literature including scientific databases and grey literature to provide an overview of the state of knowledge in a given field. A systematic review involves an exhaustive search of scientific databases with strict inclusion and exclusion criteria, to summarise the data from primary research articles to answer a very specific research question (Gregory & Denniss, 2018; Jahan et al., 2016). The different types of reviews are complementary and serve different purposes (Gregory & Denniss, 2018).

Both types of review have strengths and limitations. It is generally believed that a systematic review is more methodical, less biased and provides stronger evidence than a narrative review (Bryman, 2016), however systematic reviews may miss some very interesting and relevant data due to the strict inclusion/exclusion criteria (Gregory & Denniss, 2018). The narrative review is less structured and open to bias; a less strict inclusion/exclusion criterion may result in the selective inclusion of articles which support the points being made. The attention given to some areas of the literature may be limited (Green et al., 2006). A number of researchers have developed frameworks to address this critique (Cronin et al., 2008; Levy & Ellis, 2006; Templer & Paré, 2015). The aims of the literature review completed for this thesis align with the main 5 main goals of a narrative review identified by Baumeister and Leary (1997, p.312): 'surveying a body of knowledge in a particular area, problem identification, theory evaluation and development, providing a historical development of theory and research on a relevant topic'. Therefore, a narrative review was identified as the most appropriate approach for the purpose of outlining the rationale for the research as it would enable the researcher to cover a broad range of different fields of inquiry.

2.3.1 Literature review process

Searches were made of a number of databases were completed including: Web of Science, ASSISA, JStor, Psychinfo, and Medline, Government websites, charity websites (Alzheimer's Society for example), University websites (Bradford University for DCM, for example). These databases were used as they include sources within and outside the discipline of gerontology (Webster & Watson, 2002). Search terms used included: 'IG interventions, people living with dementia' and associated synonyms, social isolation, social isolation in care homes, awareness of dementia, meaningful activities. The only exclusion criterion was articles not written in English; no exclusion was placed on the date of articles to enable identification of theories that were developed a long time ago. Once articles were identified for inclusion, backward searches were completed using the reference lists, and forward searches were completed using citations listed on the databases or Google scholar; additional articles were identified in this way. Researchers were contacted directly for papers that were identified but could not be sourced through internet searches (McNair & Moore, 2010) for example. The quality of sources was judged on; the number of times a source was cited, peer reviewed articles, and reports commissioned by government departments. The literature review search was a live document which was continuously updated and refined throughout the completion of this thesis (Levy & Ellis, 2006).

The following three sections outline the main findings from the review as they relate to the specific challenges of living in the care home environment; mixed experience of care, social isolation, and a lack of meaningful activities. Finally, a section on IP as a possible solution to these challenges in the Welsh context is included.

2.4 FINDINGS FROM THE REVIEW OF THE LITERATURE

2.4.1 Mixed experiences of care

The available evidence indicates that the quality of dementia care in the UK is mixed. In 2007 the Alzheimer's Society found that care provided for *plwd* in care homes was not high quality. Questionnaires were completed by 1859 carers of *plwd*, 722 care home managers and 1,503 care home staff across the UK (Alzheimers Society, 2007). Data was gathered from care homes only, care homes with nursing, and specialist dementia care homes. Issues cited were: a lack of understanding about dementia, the label 'dementia' meant that other needs were lost, and a lack of courtesy and respect shown towards residents living with dementia; staff shortages were also implicated.

Later research, also completed by the Alzheimer's Society in 2013, which included data provided by *plwd*, reported similar findings. Questionnaires completed by care home staff and family members of *pwld* were considered alongside short surveys (36) completed by residents living with dementia. Whilst 68% of family members felt that the care that was provided was good, only 41% felt that 'the quality of life for the person living with dementia in the care home was good'.

The largest review completed on care homes in Wales to date was completed by The Older Peoples Commissioner for Wales in 2014. The review included data gathered from a number of sources; a national questionnaire which was completed by over 2,000 people 'and extensive written and oral evidence from 93 organisations' (OPCW, 2014, p.1). In addition, a team of 43 Social Care Rapporteurs from a range of background members visited 100 care homes across Wales and collected observational data, alongside the views of residents, their families and staff. The findings from this review were based around four key areas: day-to-day life, health and wellbeing, people and leadership, and commissioning, regulation and inspection. The review listed many shortcomings however, the central theme highlighted was a lack of any official recognition of Quality of Life in the delivery or assessment of residential care services.

2.4.1.1 A lack of meaningful activity

The available evidence indicates that care home residents, including those living with dementia spend lots of time unoccupied and have little opportunity to engage with meaningful activity.

The concept of meaningful activity is commonly used in the literature but has been defined in a number of ways. Phinney et al. (2007) explored the concept amongst community dwelling *plwd* and found that participants stated were involved in four types of activity: leisure and recreation; household chores; social involvements; and work-related activities. Four key factors that were identified as making the activities meaningful were: enjoyment and pleasure; connection and belonging; autonomy and identity. Similar themes were found in a study completed by Harmer and Orrell (2008) who explored the concept of meaningful activities for *plwd* in care homes amongst residents, care home staff, and family carers. *Plwd* identified four themes that made activity meaning for them: reminiscence; family and social; musical and individual. In essence both studies identified three common features of meaningful activity: active participation; activity content related to the interests and past roles of the participants; and activities that meet the basic psychological needs of identity and belonging (Mansbach et al., 2017).

Han et al. (2016) found that connectedness was at the basis of meaningful occupation for *plwd*. Based on a synthesis of qualitative studies three themes were identified: being connected to self, others, and the environment. *Plwd* wanted to continue with their previous lifestyles and engage in activities that they enjoyed and that they felt helped them retain their abilities, they wanted to connect to others to avoid loneliness, to maintain meaningful relationships, and to promote a sense of belonging. *Plwd* wanted to connect to their home and familiar environment for peace and comfort, to feel part of the community, and remain connected to nature. Tierney and Beattie (2019) proposed a framework of meaningful activity for *plwd* based on a review of the literature which revealed five key attributes that make an activity meaningful: that it is enjoyable, suited to the individual, related to personally relevant goals, engaging; and expresses and reinforces identity.

It has been acknowledged for many years that engaging older adults (Havinghurst & Albrecht, 1954 cited in Mansbach et al 2017, p.461), and *plwd* (Phinney et al., 2007) in meaningful activity relates to positive wellbeing. Provision of meaningful activity in a care home environment supports personhood (Milte et al., 2015) and is an indicator of good quality care (Milte et al., 2016; Smith et al., 2018) however high levels of inactivity is consistently reported in care homes (Eyers et al., 2012: Rahman, 2014, p.126).

The literature suggests that care home residents experience high levels of inactivity. In the Alzheimer's Society report (2007) some carers were very pleased with the level of occupation and activity provision, however 54% of respondents felt that residents with dementia did not have enough to do. The report (Alzheimers Society, 2007) noted that there were a variety of activities available which had been developed for people with dementia and staff indicated that engaging with them increased their job satisfaction, however there was not the time available to do so. One of the main recommendations from this report was that care homes should place greater emphasis on the social needs of residents living with dementia.

In 2012 Eyers et al. completed a study of activity programmes provided in English care homes, for all residents. The research was completed in 10 care homes in South East England and involved 145 residents aged 60-100. Residents were asked to complete a daily activity log for two weeks, with the support of researchers who visited the care homes on a daily basis to ask residents about their activities during the previous 24 hours. Interviews were also conducted with managers and activity co-ordinators in each of the homes involved in the research, and regular, daily 2-hour observations were completed at each of the homes, at varying points throughout each 24 hours. There was little in the way of organised activities after 4pm daily and at the weekends. Residents generally found the activities provided unattractive, age inappropriate, and dull. Therefore, the numbers participating in the activities were low; with 49% of residents participating in the morning and 58% in the afternoon. There was little consideration given to the impact of activities on resident's health or wellbeing, most organised activities were related to music, arts and crafts, and there was little awareness of residents' previous history including their likes and dislikes (Eyers et al., 2012).

In the 2013 report described earlier the Alzheimer's Society found that only 44% of family members felt that activity provision was good. Sixty-eight per cent of residents living with dementia said that they had plenty to keep them busy. Whilst 15% said that they sometimes had plenty to do 15% said that they did not. Reminiscence and life story work was a feature in most care homes. The report concluded that there was still much work to do on activity provision (Alzheimer's Society, 2013) and made the point that meaningful activities can simply involve helping out with domestic tasks.

Similar findings were reported in Wales by the OPCW (2014) who found that residents had restricted choice about activities that they could participate in. Few care homes provided the opportunity for residents to become engaged in 'meaningful occupation' such as making tea, baking, gardening, setting the table (2014, p.3). The OPCW (2014) suggested that reasons for this were predominantly risk aversion and misunderstanding of Health and Safety regulations.

2.4.2 Food and drink as meaningful occupation

Household chores, including helping to prepare meals were important to *plwd* in a study completed by Phinney et al. (2007), participants spoke enthusiastically about helping to prepare meals and wash dishes. If participants could not complete the chores, they could complete simpler tasks for example. If someone could no longer prepare a meal, they might still cut the vegetables. Sharing meals is something that care home residents living with dementia have found enjoyable (Harmer & Orrell, 2008). Research has consistently found that residents state that mealtimes are the social highlight of their day (Food for Life, 2007).

2.4.3 Psychosocial interventions involving people living with dementia based on preparing and sharing food

Psychosocial interventions for people living with dementia started in 1960s with Reality Orientation which was further developed in 1980s; the quality of early studies was weak (Moniz-Cook et al., 2011). However, thirty years later it was suggested that the quality of the research was not strong (Orrell & Woods, 1996). Many of the studies were small scale and difficult to replicate, as there were no manuals or protocol available. In 2011 a call was made for ‘a rapid and substantial increase’ in the quantity and quality of research in the area (Moniz-Cook et al., 2011). Although there have been improvements in the research rigour of recent studies, many promising interventions have not been fully evaluated and developed to implementation (Reiger & Gitlin, 2017), the evidence has not been translated into practice. Implementation studies are needed to explore the barriers to implementation (Reiger & Gitlin, 2017). This thesis includes a focus on the implementation of the intervention to identify barriers to implementation.

There has been a renewed focus on psychosocial interventions for people in care homes living with dementia for two reasons according to Lawrence et al. (2012). They suggest that this is partly due to the prevalence rates of psychiatric behaviour and symptoms among people living with dementia in care homes and partly due to the over prescription of antipsychotic medicine. There are a number of factors that underpin successful psychosocial interventions for *plwd* in a care home environment. In a systematic review of 39 qualitative papers on psychosocial interventions implemented and evaluated in care homes between 1995 and 2011, Lawrence et al. (2012) found that *plwd* felt that; connecting with others, making a meaningful contribution, and providing an opportunity to reminisce, were key factors. From the perspective of the staff the interventions allowed the staff to ‘see beyond the illness’, to get to know more about the individual and their family which in turn helped create deeper more meaningful relationships. Additionally, the interventions appeared to prompt the staff to examine their actions when caring for individuals.

The review identified the following factors as necessary for an intervention to be successful; the role of staff, a flexible intervention that could accommodate varying abilities, levels of engagement and amount of time required to commit to the intervention. It was also suggested that interventions should be completed over a length of time to allow residents to become confident with the intervention. Knowing the person was considered an essential ingredient in offering interventions that residents would enjoy and would be able to complete. This knowledge could also be utilised to support the resident throughout the intervention. Interacting with the family helped staff get to know the residents ‘likes, dislikes and capabilities’ Key challenges to successful interventions were found to be; pressures on the institution relating to time and staffing, the philosophy of the institution, and avoiding risk.

Previous research indicates that horticultural therapy (HT) defined as ‘participation in horticultural activities’ (American Horticultural Therapy Association, 2017) has been found engaging for *plwd* (Jarrott et al., 2002, Gigliotti et al., 2004, Gigliotti & Jarrott, 2005, Jarrott & Gigliotti, 2010). Jones and Ismaail (2019, p.23) found that ‘food-based activities are popular, meaningful, and a good leveller’. Indoor gardening has been found to reduce social isolation in nursing home residents (Tse, 2010). Unusually, in a five-week study on indoor gardening for residents with dementia completed by Lee and Kim (2008) all participants completed the study whereas attrition rates for research with *plwd* are usually high. Huang et al. (2009) found that a feeling of participation improved amongst *plwd* who engaged in a cooking intervention.

There is little in the literature about IG interventions in care homes based on food however the Better Care programme completed in Leicester with care homes, nurseries and primary schools is one such project (Jones & Ismail, 2019). The programme included 15 care homes and nursery school clusters over an 18-month period. Activities included cooking, eating together, indoor and outdoor gardening, and farm and community visits. The majority of the activities were developed by staff and included: water cress sandwiches, eating lunch together, making peppermint creams, life history and reminiscence. Care home staff reported a number of benefits experienced by residents including enhanced mood, improved connections, and a reduction in loneliness. The authors reported that there is ‘considerable scope for action on IG food related activities in care homes, and that ‘food formed a good focus for IG activities’ (Jones & Ismail, 2019, p.25).

Preparing and sharing food was considered an interesting basis for an IG intervention as older and younger generations have experienced ‘different consumption spaces’ where the types of food eaten, and the way in which they are eaten differ. Eating practices differ with time and place; it is potentially interesting for both generations to learn about the differences experienced by different generations. Baking, for example, is a way of bridging the generational gap; ‘appealing to children with grandmother having the skills to transmit’ (Knight et al., 2014, p.309). The preparing and sharing of food are areas which can maintain connection and evoke memories (Papachristou et al., 2013).

There are a number of other reasons for choosing the acts of preparing and sharing food as a focus for the intervention. Firstly, these activities are familiar to all and reflect the ordinariness of life, a context which may be lacking or difficult to create in a care home environment. Second, they have the potential to enhance the wellbeing of care home residents (Jones & Ismail, 2019) and third, they have the potential to address malnutrition which is an issue in care homes (NICE, 2011).

In a study which assessed the outcomes of the implementation of a new model of care aimed at creating 'an ordinary life' for residents in a special unit for *plwd* in residential care, Brannelley et al (2019, p.758) noted that: 'In an ordinary life, people exercise choice about where they live, who they associate with, and what they do each day'. Taken in the context of *plwd* however, this statement cannot be applied at face value when it comes to a residential care home setting. Gjernes and Måseide (2020, p.1772) through their research in a Norwegian care home for *plwd*, emphasise the importance of 'ordinariness' as an essential element of dementia care which can be integrated through 'settings, activities and identities that are experienced as common, well-known and unexceptional'. The authors illustrate well the significance of this "ordinariness" through a simple example: 'To spread butter on (residents') sandwiches (by a caregiver) is taboo here; each resident is supposed to do what he or she is able to do' (p.1776).

Similarly, completing household chores was probably an integral part of the ordinariness of home life. Phinney et al's (2007) study involving interviews and observations with eight community based older adults living with mild to moderate dementia illustrated the importance of chores to *plwd*. In the study participants spoke enthusiastically about helping to prepare meals and wash dishes. However, the opportunity to become involved in these types of activities for *plwd* once they are in a care home context is less obvious. In Wales, there is evidence to suggest that the care home environment is often lacking in meaningful, or 'ordinary' activity such as making tea, baking, and gardening (OPCW, 2014).

Whilst there are a number of activities other than those focused on food that have successfully formed the basis of IG interventions in care homes involving *plwd*, notably with an emphasis on entertainment and creativity, see for example, poetry (Garrie et al, 2016); storytelling (George et al, 2014); art (Lokon et al, 2012, 2017, Sauer et al 2014); singing (Harris & Caporella ,2014); dance (Canning, Gatetz and Blakeborough (2020), none offer the universality of shared experience that preparing and sharing food does. Participants may like music, and may relate to, and feel relaxed when creating a piece of art, but neither are vital to physiological sustenance. Food-based activities therefore provide the opportunity to become or remain immersed in activities of daily life, the “normal” of things.

When it comes to the wellbeing and quality of life for *plwd* who live in a care setting, there is some evidence to show the benefits of shared dining experiences. Regardless of cognitive function, research has consistently found that residents find mealtimes are enjoyed and seen as the social highlight of the day (Food for Life, 2007; Harmer & Orrell, 2008). Sharing meals is also a common element of social interaction and as such, has the potential to stimulate friendship making (Jarrott & Smith, 2010, p.112). Food can also stimulate the senses and our memories which may in turn, provide a connection to someone’s life story (Jones & Ismail, 2019). Reflective of this are IG interventions in care homes for residents living with dementia which involve an element of reminiscence (see for example, making scrap books [Chung 2009; Lokon-Shute et al 2004]; using reminiscence cards [Wood et al., 2017]). These interventions have resulted in an improvement in Qol and cognitive function amongst *plwd*.

Finally, anything that engages *plwd* in food preparation and sharing can potentially help address malnutrition, a well-documented but often ignored issue amongst care home residents (NICE, 2011). Agarwal et al’s narrative review of the literature on the ‘identification, prevalence, associated risk factors, consequences, and management of malnutrition in residential aged care settings’ (2016, p. 70) in developed countries, found that approximately half of residents of care homes for older adults were experiencing malnutrition. Poor nutrition in itself may lead to a number of interlinked problems including low mood, decreased social interaction and poor wellbeing outcomes (Ismail & Jones, 2019).

The clear need to address risks of malnutrition in care contexts notwithstanding, few IG interventions involving care homes accommodating *plwd* have explored this domain. Whilst some interventions have involved baking (Jarrott & Bruno, 2007; McNair & Moore) and sharing meals (Jarrott & Bruno, 2007), at the time of submitting this thesis, I only found one study by Jones and Ismail (2019) which focused on a more holistic approach to food-based activities in which *plwd* were engaged in elements of preparation and sharing (sowing plant-based seeds outdoors, making sandwiches and sweets, keeping chickens, and sharing a meal).

In sum, the available evidence suggests that preparing and sharing food could provide a good basis upon which to design the intervention, and was chosen as a basis for this intervention as it has the potential to make life in a care home more of an ‘ordinary’ experience, and to improve the physical health and wellbeing for residents. Whilst other IG interventions have used reminiscence and creative activities to help engage *plwd* in entertaining and creative expression, preparing and sharing food not only encompasses these elements, but also has the potential to provide them with an ordinary, and potentially more purposive life.

2.4.4 Social Isolation among care home residents

Residential care historically focused on physical care, and fit into Goffman’s description of a ‘total institution’ (Goffman, 1961/2009); places where groups of people with similar characteristics (older adults for example) share every aspect of their lives (eating, sleeping, playing) together. Institutional living may result in little interaction with the external environment which has the potential to create social isolation and a level of ‘separateness’. The report completed on care homes in Wales found that many people became institutionalised, and have little choice or control over their lives. Their individuality and identity diminish, and they experience little social stimulation which results in withdrawal which negatively affects their wellbeing and quality of life (OPCW, 2014, p.13).

A number of definitions have been provided for social exclusion. Social exclusion has been described by Moffatt and Glasgow, 2009 cited in Villar et al (2021, p.297) as: ‘separation of individuals and groups from mainstream society’. Burholt and Aartsen, (2021, p.78) state that: ‘exclusion from social relations is a situation in which people are disconnected from adequate levels and quality of intimate relationships, social networks, social support, and/or social opportunities to participate in the wider society'. People living in care homes are at high risk of social exclusion, residents living with dementia face a higher risk as they may experience communication issues and may require high levels of support (Cahill, 2018 cited in Villar et al., 2021, p.298).

2.4.5 Definitions of Intergenerational Practice

Core to this thesis is the construct of "intergenerational practice" (IP). The purpose of this section is to highlight some of the challenges the construct raises and to clarify how it has been interpreted in the thesis.

The concept of 'generation' is used in various ways, although a generic understanding is that generations can be conceptualised at two levels, familial and societal (Hilloat-Nallétamby, 2010). A familial generation relates to kinship relationships such as child, mother, grandfather (Gilleard & Higgs 2002, Keating et al, 2015). Although 'generation' as a sociological phenomenon encompasses chronological age at the micro-level of individuals (Weiss & Zhang, 2020), at a societal level, generations are conceptualised as cohorts of people who share a timeframe in which they were born. As such they share exposure to historical events, a war for example, and it has been argued, a 'generational consciousness' or world view associated with these shared experiences (Gilleard & Higgs 2002; Keating et al, 2015). To add further complexity, the birth cohort ranges of societal generations vary (Rudolph et al, 2020), although there are a number of recognised generational cohorts which include 'Millennials' (born approximately 1981-1996), 'Baby Boomers' (born approximately between 1946-1964) and the 'Silent generation' (born approximately between 1926-1945). A further distinction is also made between *inter*generational groups, where a given experience or phenomenon is shared across different societal or familial generations and *intra*generational exchanges, relations, for example, occurring within and between members of a single societal or familial generation.

2.4.6 Intergenerational Practice as a construct

One of the main challenges posed by the construct of "intergenerational practice" (IP) is the lack of consensus about its meaning and nature, or of its objectives and component generations, so a clear definition is not readily available.

Kaplan (2001, p.43) defines IP as: ‘A vehicle for the purposeful and ongoing exchange of resources and learning among older and younger generations for social and individual benefits”. Pain (2005, p.6) states that: ‘IGP usually consists of small scale, intensive projects in particular settings, where older and young people are brought together around planned activities. These interventions seek to enrich intergenerational relations and aim to have a range of positive outcomes for communities’

In the UK context in particular, Hattan-Yeo (2006, p.2) offers a broader definition and clarifies aims:

> ‘Intergenerational practice aims to bring people together in purposeful, mutually beneficial activities which promote greater understanding and respect between generations and contributes to building more cohesive communities. Intergenerational practice is inclusive, building on the positive resources that the young and old have to offer each other and those around them”.

Subsequently, Hatton-Yeo (2015, p.284) questions the possibility of having one single definition of IP and states that ‘what matters is that we improve the lives of generations and their families’. This lack of consensus about the characteristics of IP notwithstanding, there are commonalities across the definitions; an intergenerational focus through the involvement of a number of generations, a focus on outcomes, and on relationships based on sharing (Sanchez et al, 2007).

Furthermore, there is no consensus on other aspects of IP, for example the number of generations that should be involved (Granville, 2002), nor the age of participants. In the late 90s, an international working group (UNESCO, 2000) established what can be seen as a generic description of IP which was essentially a benchmark list of what would constitute a successful intergenerational project. One of these was: ‘they can involve multiple generations but must include at least two nonadjacent and nonfamilial generations’ (UNESCO 2000, Hatton-Yeo, 2015, p.283). To date, although IP practice has involved different age pairings, it typically includes young people (normally under 25) and older people (typically over 50) which satisfies the criteria of ‘nonadjacent generations’ (Hatton-Yeo, 2006, Beth Johnson Foundation, 2011). However, this does not preclude the presence of three generations; for example, those classed by chronological age as older cohorts (65+) may also be stratified further into the societally defined generations of the “Baby Boomers” and “The Silent Generation”. The issue is therefore how to clearly identify the numbers and societal “identities” of generations involved and with a clear rationale for doing so.

Whilst it is possible to trace the broad aims of IP in terms of facilitating contact between younger and older adults to promote understanding between both generations, enhancing relationships and reinforcing social cohesion (Philips, Ajrouch & Hillcoat-Nalletamby 2010), the similarities end there.

In terms of their aims, historically, IPs were developed in North America in the late 1960s and 70s to address societal shifts in family relationships which at the time, were perceived as generating problems of generational segregation, societal dislocation and familial dissonance (Newman, 1997). IPs began to emerge in Europe, and more specifically in the UK and Wales in the new millennium, again with the aim of addressing societal issues such as social isolation and the need to promote social cohesion and age friendly societies (Pain, 2005; Beth Johnson Foundation, 2018; Welsh Assembly Government, 2003).

With such a wide agenda of societal issues, IPs are now difficult to classify in terms of their aims. Mannion (2012) maintains that at least one must be to facilitate reciprocity whilst others specific they should be determined based on the needs and interests of the groups. In their review of 15 peer reviewed papers on IP’s, Vieira and Sousa (2016, p.409) identify three broad types of aims, some IGs aimed solely at promoting IG relationships, some promoting this and another goal (for instance students and *plwd* engaging in activities together to enhance the wellbeing of older adults and attitudes towards dementia amongst students) and a third group where IPs were actually the vehicle for achieving a secondary goal such as sustainable waste management. For example, in an educational waste management programme, which involved schoolchildren and their parents in the north of England the amount of recycling in the area increased and the amount of residual waste decreased (Maddox et al, 2011).

Finally, identifying the physical location in which IPs are set presents challenges for the researcher. For example, choosing a residential care setting in which to develop an IG activity involving both young and old may challenge any expectations of providing age stratified activities where older people are invited to engage in “age appropriate” activities by themselves. Vieira and Sousa (2016, p. 410) notes that this requires the researcher to transcend “institutional frontiers” and “mental boundaries”. In short, another challenge of the IP is to choose a physical environment which will enable the transcendence of otherwise “age conditioned” realities and interactions.

For my research, the choice of a residential setting designed to accommodate *plwd* as the experimental context in which to carry out the IP provided this challenge. As Goffman (1961) observed, the care home environment of today may still represent a “total institution” encompassing residents’ experiences of work, leisure and sleep all under one roof. For Goffman in ‘total institutions’, all aspects of a resident’s life are conducted under a ‘single authority’, with many other residents with similar characteristics who are treated in the same way and expected to do the same thing, in the same order, at the same time. The daily schedule of events is planned by the authority to meet the aims of their institution”. A ‘total institution’, in this case the care home, is characterised by ‘the barrier to social intercourse with the outside and to departure that is often built right into the physical plant, such as locked doors…’ (Goffman 1961, p.1). Designing an IP which deliberately aimed to bring two worlds together, that of the “outside community” represented by young adult living in the community, to engage in the physical space of the “inside institution” of the care home setting, reflects the type of innovative design required to go beyond these institutional boundaries.

In sum, there are well recognised challenges and complexities when designing and carrying out IP projects, including lack of theoretical and conceptual frameworks which leads to poorly articulated definitions and problems of study design in terms of which groups to include and why; diverse and complex aims, and the importance of matching physical location with IP project aims and participants.

The rationale for the research design I adopted for an intergenerational intervention is elaborated fully in Chapter 4 sections 2, 3 and 4. I also discuss in some depth the challenges that designing and undertaking an IP study for my research have entailed in Chapter 9, section 3. This thesis is based on the definition of IP offered by Hattan-Yeo (2006), not only because it is commonly used, but also because it is a good fit with the aims of this thesis. In this thesis, although they were not purposively selected on this basis, participants represented three societal generations; younger participants as ‘millennials’, and the older participants as ‘baby boomers’ or members of the ‘silent generation’. The focus of this research has been on observing the intergenerational effects that participating in the study has on older people and younger adults, so the effect of shared activities across different generations

2.4.7 The use of IP to address social isolation and raise awareness of dementia in care homes-initiatives in Wales

IP receives special attention in the dementia plans of the WHO and the Welsh Government (WHO, 2017; Welsh Assembly Government, 2003; Welsh Assembly Government, 2008). IP aims to improve relationships and understanding across generations by providing the opportunity for people from both groups to meet and engage in co-operative activities, with the purpose of sharing knowledge and experience (Phillips et al., 2010).

In 2003 the Welsh Assembly Government (WAG) published ‘The Strategy for Older People in Wales’ to address the issue of an ageing population (WAG, 2003). Phase one covered the years from 2003 to 2008, and phase two covered the years from 2008 to 2013 (WAG, 2003). The 2003 strategy included an action point to create a programme, which would promote IP in Wales. As a result, in July 2003, the Beth Johnson Foundation (BJF), a specialist organisation which addresses IG issues and themes, was commissioned to work with partners across Wales to develop an IG strategy (WAG, 2008). In 2003 the BJF established the Wales Centre for Intergenerational Practice (CCIP) in partnership with the University of Glamorgan (in 2004), IG courses were delivered in Lampeter (Institute of Welsh Affairs, 2007), and online IG courses (BJF, 2018). An approved standard for organisations that provide IG projects and programmes (BJF, 2008) was developed alongside a network of individuals and organisations with an interest in IP. However, none of these appear to still exist, despite the early interest in IP progress in Wales has been inconsistent.

Part two of the strategy for the OPCW was published in 2008 (WAG, 2008); social inclusion was listed as one of four key factors to be addressed. The document recommended encouraging IP, as a solution, and as a result the IG strategy for Wales was published in 2008 ‘Building a Society for All Ages’ (WAG, 2008). This document is based on the vision for Wales of ‘strong, vibrant and sustainable communities where there is active participation between services and citizens to achieve better outcomes’ (WAG, 2008, p.8). The aim of the proposed strategy was to embed IP into the ‘whole approach to communities, citizenship and integrated government’ (WAG, 2008, p.17).

In 2012 the Welsh Local Government Association which supports authorities to develop policies produced guidance for people planning IP (Welsh Local Government Association, 2012). Despite a dearth of evidence supporting the effectiveness of IG in Wales, in 2017 the Children’s Commissioner for Wales and OPCW together launched a set of online resources to support communities to establish IP. The resources included case study videos (OPCW, 2016), and a tool kit to provide information and guidance for how to set up a project (OPCW, 2016).

There is strong popular interest in IP in Wales with examples shown on social media, but with little evidence of their evaluation in the way of academic studies. Examples of IP now regularly appear on social media, such as Twitter, and in the news. Some of the most recent examples include an S4C documentary on ‘Hen Blant Bach’, a project which brought nursery children and older adults together in a day care setting in Caernarfon for a 3-day programme. During the 3 days participants socialised, engaged in activities, and ate together; the project was observed by two Psychologists (Professor Bob Woods and Dr. Catrin Hedd) from Bangor University (Prifysgol Bangor, 2016; Walford, 2017). While there was no published evaluation at the time of submitting this thesis, initial results suggest that benefits were experienced by both groups of participants. Other recent examples include a project which involved pupils from St Joseph school who planted seeds with residents in Woffington House care home in Tredegar (Woffington House, 2018). These interventions did not specifically focus on *plwd* but did not exclude them; therefore, it is fair to assume that *plwd* formed part of this study. The interventions focus on preschool and school aged children and are encouraging; however, while the general consensus is that these interventions result in benefits for children, older adults, and communities there is a lack of published evaluations of such interventions.

The evidence base for IP is predominantly based in the USA, so not necessarily directly relevant to the Welsh context. For example, Springate et al. (2008) reviewed the UK IP literature to explore what IP had been completed, what outcomes were achieved, and for whom, and the characteristics of effective programmes. Forty-three sources were identified, including only 12 academic research studies, the remaining documents were a mix of project evaluations, discussion papers on IP, descriptive accounts of projects, literature reviews, and practice guides. Only 2 sources were completed in Wales, neither one was peer reviewed. Three outcomes were found across both groups; children and young adults, and older adults: increased understanding, friendship, and enjoyment and confidence. The research evidence base for the use of IP specifically to increase awareness of dementia and improve wellbeing for *plwd* is discussed in detail in Chapter 3. However, there is also evidence highlighting the challenges and limitations of IP. For example, short term funded projects may create more damage and leave older people feeling more isolated if no other replacement activities fill the gap (Welsh Government, 2019).

In the OPCW care home review (2014) 'requirements for action' included the promotion of befriending activities to support meaningful contacts for residents. The OPCW (2018) impact and analysis report which assessed progress against the action requirements identified several IG initiatives, but suggests that there has been 'limited progress' against 'Befriending'.

In sum, what this overview of IP initiatives in Wales suggests is that despite earlier interest from policy makers and practitioners alike, progress appears to have fluctuated, with services that were developed such as the IG centre and online training no longer appearing to exist. Given these lacunae, it is important for Wales to build a more robust evidence base about IP; the current study aims to contribute to this

2.5 CHAPTER SUMMARY

This chapter outlined the context in which the study was completed; two care homes in Wales. There are plans, policies, guidance, and legislation in place in Wales that place an emphasis on wellbeing and are aimed at the provision of good dementia care throughout the lifespan of people living with the condition. However, the available literature suggests that *plwd* may have mixed experiences of care, and that care home residents may experience social isolation and a lack of meaningful activities. The literature reviewed in this chapter indicates that psychosocial interventions based on preparing and sharing food, and IP practice are engaging for *plwd*. There is therefore, a reasonable assumption that a psychosocial intervention based on IP and preparing and sharing food has the potential to address the issues of social isolation and lack of meaningful activities, and result in enhanced wellbeing for *plwd*. The next chapter will present a review of IG interventions that have been completed with people living with dementia, with a focus on the care home environment.

3 CHAPTER 3: THE LITERATURE REVIEW AND THEORETICAL FRAMEWORK

The aim of this chapter is to review the academic literature, which focuses specifically on IG interventions involving older adults living with dementia. The purpose is to identify what is already known about IG for *plwd;* assess how previous researchers have completed research in this area; identify relevant theories; revisit the original research aims in light of this knowledge and identify research questions. Findings from the review subsequently informed the theoretical framework underpinning the research, the design of the intervention and its delivery (see Chapter 5) and interpretation of the findings (see Chapters 7 & 8). The chapter begins with discussion of the literature review approach and process adopted for this purpose; then presents findings relating to IP involving *plwd* and others. This is followed by a critical overview of Kitwood's philosophy of care (1997) and Allport's contact theory (1954). A discussion of how this informed the intervention and research design. completes the chapter.

A review protocol was designed as suggested by Booth et al. (2016; Dickson et al., 2014), to ensure consistency and to eliminate bias. The protocol can be found at Appendix 1. This review was based on the nine steps involved in a systematic review as identified by Boland et al. (2017, p.10): identifying scoping searches, identifying the review question and writing a protocol, literature searching, screening titles and abstracts, obtaining papers, selecting full text papers, quality assessment, data extraction, analysis and synthesis, and writing up and editing.

The majority of studies identified in the literature search originate from the USA and the earliest which targeted *plwd* were completed in the 1990s (for example Newman & Ward, 1992-1993; Ward et al., 1996; Camp et al., 1997). Later studies have been completed in Hong Kong (Chung, 2009), and the UK (Di Bona et al., 2015; Wood et al., 2016; Wood et al., 2017).

Twenty-eight articles involving *plwd* were identified for inclusion in the following review as a result of the combination of searches made. A number of these sources originated from research communities or clusters and relate to the same IG intervention. Of the studies reviewed, IP interventions have included different age groups in the ‘young’ category (preschool children, school children, and college or university students), the ages of *plwd* ranged from 50 to 95. IG interventions for *plwd* are complex interventions: ‘interventions that contain several interacting components’ (Craig et al., 2008, p.1) which means that research articles include many details. The questions that this review sought to address were: *What effects do IG interventions have on older adults with dementia and younger people? What factors of the intervention make a difference? What methodologies have been used to investigate the issue? How effective are they? And what theories have been used to explain the results?* with consideration given to the different age categories; of most pertinence to this thesis is the literature involving college or university students as the younger group, therefore the section will start with these.

3.1 FINDINGS-IP INVOLVING P*EOPLE* L*IVING* W*ITH* D*EMENTIA* AND STUDENTS

Twelve articles were reviewed, which are presented in Table 1. The IP programmes involved volunteering and/or service-learning opportunities for the students. Service learning (SL) has been described in a variety of ways, for example: Yamashita et al. (2011, p.140) describe service learning as ‘a form of experiential education in which students become actively engaged in a community service-project that helps them connect theory to practice’. Tam (2014, p.401) define this as ‘a reciprocal partnership among individuals of different ages who work together by sharing skills, beliefs, and knowledge’. Programmes typically involve college or university students who volunteer with *plwd* in a variety of settings, in return for course credits. The terms ‘volunteering’ and service-learning’ may be used interchangeably although there are some subtle differences; one key difference is that service learning is part of an academic course that starts prior to, and continues after, the service-learning experience, in essence service learning is part of a course (Global Vision International, n.d.). SL can involve a clinical placement, or may include non-clinical or generic activities, such as supporting residents to complete a scrapbook on their life (Fruhauf et al., 2004; Lambert-Shute et al., 2004). The intervention completed for this thesis was not, in strict terms SL as it was not part of an academic programme of study, but was offered to students as an extracurricular volunteering opportunity; students did not gain course credits for their involvement but a note was included on their student record that they had volunteered in the programme. Therefore, non-clinical IP service learning and extracurricular volunteering programmes were included in the literature review; no distinction was made between them. Ten articles focused on IP programmes completed in the USA, one in The United Kingdom (England) (Wood et al., 2016; Wood et al., 2017), and one in Hong Kong (Chung, 2009).

The context of the IP varied; from day care, assisted living, and long-term care facilities. Seven articles involved art and creative activities, three involved reminiscence, and two focused on IG choirs. Individual sessions lasted between 1 and 3 hours, with a typical session length of 90 minutes. Programme length ranged between 4 and 12 weeks, however the poetry session completed by Garrie et al. (2016) was an individual session which lasted an hour. No information was provided on the duration of the scrapbook intervention discussed by Fruhauf et al. (2004; see also Lambert-Shute et al., 2004). All studies assessed changes in student attitudes; few evaluated the intervention from the perspective of the *plwd* (Chung, 2009; Harris & Caporella, 2014, 2018; Sauer et al., 2014).

3.1.1.1 Methodologies used effectively

All interventions assessed student attitudes towards *plwd*, their knowledge of dementia, and/or comfort with dementia using a repeated measure pre-test post-test post design. A variety of questionnaires and scales were used, however, only two were designed specifically for use with *plwd*; The Chinese version of the Dementia quiz and the Dementia Attitude Scale (DAS) (O'Connor & McFadden, 2010), which was the most commonly used questionnaire (Garrie et al., 2016; George et al., 2013; Lokon et al., 2017).

Studies also explored the student experience of the intervention with student journals completed during the intervention (George et al., 2012; Yamashita et al., 2011) or questionnaires and scales designed by the researchers (Chung, 2009; Wood et al., 2017), qualitative questions on Google-Doc (George et al., 2014), plus semi-structured interviews (Garrie et al., 2016), and focus groups (Lambert-Shute et al., 2004). Harris and Caporella (2014, 2018) used an innovative phenomenological word task to assess changes in student attitudes. Students were asked to write 10 words which came to their mind when they thought of Alzheimer’s disease or dementia. The words were classified as negative, neutral, or positive, students were also asked open-ended questions such as: ‘what have you learned about dementia, people living with dementia, and their family members so far from this experience?’, half way through the intervention, and after the concert.

Studies that evaluated the intervention from the perspective of the *plwd* used validated quantitative measures: Chinese versions of the MMSE, the Qol-AD, and the Geriatric Depression Scale, completed by a proxy, observation using a modified version of the Greater Cincinnati Chapter Wellbeing Tool (Sauer et al., 2014), and focus groups (Harris & Caporella, 2014, 2018). Only one study, completed by Sauer et al. (2014) incorporated an experimental and control group of *plwd* to the research design.

3.1.1.2 Outcomes for students

In general improvements were recorded in knowledge, attitudes, and comfort across all of the studies. Chung (2009) additionally reported an improvement in the self-esteem of students. There were a number of interesting results found in studies that used the DAS (O'Connor & McFadden, 2010). George et al. (2013) found a post intervention increase across 19 of the 20 items of the questionnaire but no change on factor 6 ‘I feel uncomfortable being around people with Alzheimer disease and related dementias (ADRD)’ whilst Lokon et al. (2017) found statistically significant increases in all factors except item 11 ‘it is important to know the history of people with ADRD’. The increases that George et al. (2013) identified ranged from an increase of 1.63% for ‘I admire the coping skills of people with ADRD’ to an increase of 50.65% for ‘it is rewarding to work with people with ADRD’. Garrie et al. (2016) also found an overall increase in the DAS scores with the greatest increases recorded against the following four factors: ‘people with ADRD can enjoy life’, ‘we can do a lot to improve the lives of people with ADRD’, ‘I feel frustrated because I do not know how to help people with ADRD’, and ‘I am not very familiar with ADRD’. Qualitative data supported these findings; students expressed greater comfort with *plwd* (George et al., 2014; Lambert-Shute et al., 2004; Lokon et al., 2012; Garrie et al., 2016), and increased confidence (Lambert-Shute et al., 2004: Garrie et al., 2016). Harris and Caporella (2014) found that the attitudes of students changed across all four cohorts; in the first study, for example a reduction of 42% in ‘negative’ words, and an increase of 50% in ‘positive’ words was recorded. It can be argued that whether a word is ‘negative, neutral, or positive’ is subjective; there does not appear to be any discussion in the journal articles as to how these words were classified.

3.1.1.3 Outcomes for people living with dementia

Chung (2009) found an overall improvement in QoL, cognitive function, and a reduction in depression. Sauer et al. (2014), found that *plwd* in the OMA IP intervention experienced higher intensity scores for engagement and pleasure, but lower intensity scores for disengagement compared to *plwd* who completed the traditional arts intervention. Harris and Caporella (2014, 2018) found that *plwd* and their family members had enjoyed time together, and that they had experienced a lessening in social isolation.

The evidence cited provides good indication of the potential of IG service-learning programmes with *plwd* to raise awareness of dementia amongst students. The studies reviewed here however provide less evidence of the potential of such interventions to improve the well-being of *plwd*. There are limitations to consider in the studies; for example, while repeated measures pre and post survey designs can indicate changes as a result of the intervention, it must be recognised that other factors beyond the intervention, may also be implicated. It is also difficult to isolate the IG element as the underpinning reason for change, as each intervention is complex, and involves many factors. For example, it is difficult to state with certainty that it was the IG element in the OMA programme that resulted in greater engagement and pleasure for *plwd*, as the traditional arts activities and OMA programme differed in other ways too. For example, in the OMA programme *plwd* were supported by students on a 1:1 basis, whereas the traditional arts activities were completed on a group basis. The journal articles highlighted some issues around the intervention process, for example some students found the process emotional, the support offered insufficient, and completing the intervention alongside existing commitments challenging.

Table 1: *IG interventions involving plwd and students*

Authors and country	Activity, context, and underpinning theory	Duration	Participants	Study design	Measures used
Chung (2009) Hong Kong	A service-learning intervention completed in a community day care centre or the participant's home. The activity was reminiscence: making a personalised life story book	A 12-week programme. One session each week of approximately 90 mins	51 adults with early dementia 121 youth (15 -25)	Adults: Pre-test, post-test, Single group Students: A scale and a quiz were completed pre-test, post-test, single group A questionnaire was completed post intervention	Chinese version of: 1. MMSE QoL-AD 2: Geriatric Depression Scale Chinese version of: 1) The Dementia Quiz. 2) Self-esteem scale 3) 20 item questionnaires developed by researchers for feedback
Garrie et al. (2016) USA	A poetry workshop was completed in a dementia unit, in a continuing care community. A retirement community covering independent living, assisted living, and nursing care.	1 hour preparation before a 1-hour workshop.	No details were provided of *plwd*. 14 medical students enrolled at Rowan University School of Osteopathic Medicine.	Students only: Pre-test, post-test, single group.	DAS scale (O'Connor & McFadden, 2010), plus semi structured interviews
George et al. (2014) USA	'Timeslips' programme: storytelling using pictures completed in a care home	4 weekly sessions of approximately 90 minutes.	20 residents with advanced dementia and 22 fourth year medical students.	Students only: Pre-test, post-test, single group.	DAS (O'Connor & McFadden, 2010)
George et al. (2013)	As above	As above	As above	Qualitative data was gathered from 'Google-Doc' where students responded to open ended questions, before and during intervention. A focus group was also held post intervention, and all data pooled.	Open ended questions about: their level of comfort working with *plwd*, their perceptions of the creativity of *plwd*, and perceptions of the residential home.

Authors and country	Activity, context, and underpinning theory	Duration	Participants	Study design	Measures used
Harris and Caporella (2014) USA	An IP choir composed of community dwelling *plwd* and their carers' *Contact theory (Allport, 1954)* .	8 weeks rehearsals lasting up to 90 minutes plus final performance	13 students aged between 18 and 22, and 6 people with early-stage dementia or mild cognitive impairment and 7 family members	Students: Pre-test, post-test *Plwd* and family members attended focus groups at week 6	Phenomenological word task 'When you hear the word dementia what images come to mind? plus open-ended questions
Harris and Caporella (2014) USA	As above	As above (4 cohorts: 2013,2014,2015,2017)	In total 62 students were involved, and 43 people with early-stage dementia or mild cognitive impairment.	Students: Pre-test, post-test *Plwd* and family members attended focus groups at week 6	Phenomenological word task 'When you hear the word dementia what images come to mind? plus open-ended questions
Lambert-Shute et al. (2004) USA	Scrap book project involving the personal histories of *plwd*, completed at a day service. *Contact theory (Allport, 1954), Personhood, Kitwood (1997),*	15-20 hours of onsite work during 1 semester	8 service learners enrolled on an 'Issues in Aging or Sociology of Aging' course. No details provided about *plwd*.	Students only: Post intervention	Focus group
Lokon et al. (2012) USA	Opening Minds through art (OMA) completed at a continuing care retirement community. *Personhood, Kitwood (1997)*	90 mins per week for 10-12 weeks culminating in a gallery exhibition.	Approximately 12 older adults living with moderate to late-stage dementia and 59 students, over time.	Students only: Written journals were completed after OMA sessions throughout the programme	Journals with prompts, for example; 'what have you learned? What were the best parts?

Authors and country	**Activity, context, and underpinning theory**	**Duration**	**Participants**	**Study design**	**Measures used**
Lokon et al. (2017) USA	Opening Minds through art (OMA) completed with *plwd* living in nursing homes, and with *plwd* who live in the community, and attended a day care centre. *Personhood, Kitwood (1997)*	As above for one semester	156 students between 18 and 45. Who were on gerontology, social work, and education courses. No details about *plwd* were included.	Students only: Pre-test, post-test survey	Dementia Attitudes Scale (DAS) (O'Connor & McFadden, 2010)
Sauer et al. (2014) USA	Opening Minds through art (OMA) delivered in long term care facilities. *Personhood: Kitwood (1997)*	60 mins per week for 12 weeks. culminating in an art exhibition.	38 older adults with moderate to advanced dementia, and trained student volunteers.	Adults only: Repeated measures with a control group. Adults were observed at a number of timepoints during the intervention.	Modified version of the Greater Cincinnati Chapter Wellbeing Tool (GCWBT).
Wood et al. (2017) UK	Interaction with reminiscence cards as prompts completed in care homes.	4 care home visits of 3 hours	13 students: 6 physiotherapy, 7 learning disability nursing students	Students only; cross sectional data completed after the intervention.	A survey designed by the researchers including 32 items assessed on a Likert scale and 7 open ended questions.
Yamashita et al. (2011) USA	Opening Minds through art (OMA) delivered in continuing care retirement communities.	No details included about length of sessions but programmes were completed over 2 semesters.	55 students from Gerontology and Sociology courses, aged 15-29.	Students only: pre-test post-test surveys, and/or journals.	An adapted version of SAILS Questionnaire (Pillemer &Schultz, 2002). Journals (with prompts)

3.2 FINDINGS-IP INVOLVING PRE-SCHOOL CHILDREN

Eight studies were reviewed in this section, which are presented in Table 2, were all completed in the USA. The majority were completed in shared sites, a concept that has not typically been used in the UK or Wales. The activities themselves varied and included music, movement, Montessori based activities, gardening and sharing lunch. Activity sessions typically lasted about 45 minutes, the duration of the programmes differed from 5 weeks to a year. All studies used a control group or condition to compare with the treatment IP.

All studies assessed the outcomes for *plwd* using observational measures. Jarrott and Bruno (2003, 2007) were the only researchers to use a validated observational measure (DCM), and supplemented observational data with interviews completed by *plwd* and their caregivers. Two studies assessed outcomes for children too (Jarrott & Bruno 2003, 2007; McNair & Moore, 2010).

Outcomes for children were mostly positive, with some exceptions. Children enjoyed interacting with the older adults, and benefitted from one-to-one attention, and ‘exposure to diverse individuals’ (Jarrott & Bruno, 2007, p.250), and provided more positive words and pictures of *plwd*. However, there were some exceptions; of the twenty-four parents who completed surveys relating to their child’s experience during the SSIP, three parents mentioned that their child did not want to join in the IG initially or did not want to ‘stop playing to join in the activities’ (Jarrott & Bruno, 2007, p.250).

Outcomes for older adults living with dementia, across all studies reviewed, included: increased engagement, enhanced mood, and less anxiety. However, a number of negative experiences were also reported including: noise, disagreements, feeling disliked, and increased anxiety. Newman and Ward (1992-1993) and Ward et al. (1996) found a spontaneous increase in touching and extending hands when children were present, and a very small (non-significant) reduction in agitation. Camp et al. (1997) found that *plwd* could act as mentors during Montessori based IP activities, and that residents experienced a reduction in apathy when engaged in IP activity. More constructive engagement, and less negative types of engagement (passive, and non-engagement for example) were observed when children were present (Camp et al., 2004; Lee et al., 2007). Camp et al. (2004) also found that *plwd* experienced more pleasure in the sessions with children than in the standard activity sessions. The findings relating to fear and anxiety were mixed: one group of participants living with dementia showed a slight decrease in anxiety/fear in the sessions with the children although a second group showed slightly higher levels in the sessions with the children. The researchers stated that there was very little anxiety/fear evident therefore the levels recorded may not be ‘clinically meaningful’ (Camp et al., 2004, p.171). There were no changes observed in sadness, which was rarely observed during the study. Jarrott and Bruno (2003, 2007) found that mood was higher amongst the treatment group than the control group in general, and that the mood amongst the treatment group was higher when they engaged in IG activities than non-IG activities. This may show distinctions between the groups in general; as study did not collect baseline data there is no way of knowing whether this group generally experienced more positive mood and behaviour.

Caregivers stated that *plwd* had experienced improved social interactions, mood, self-confidence, and happiness on the days that they interacted with the children. Data gathered directly from the older adults indicated that they experienced more positive mood, and that they liked ‘interacting with and caring for the children, watching the children’ (Jarrott & Bruni, 2007, p.251); they liked the energy and friendliness of the children. There were however a number of negative responses to the IP from caregivers and *plwd*. Two caregivers expressed concerns for their family member on the survey which included; ‘noise, disagreements between the adult and a child, and feeling that their relatives’ talents were not used’ (Jarrott & Bruno, 2007, p.250). Twenty-one adults stated that there was something that they did not like about the IG activities including: ‘noise, commotion, and children’s impoliteness’ (from a list of prompts), and ‘disliking doing things with children, interfering with the participant’s activity, and feeling that children did not like the participant’ (Jarrott & Bruno, p.250). However, it was not clear whether this data had been provided by participants who had chosen to join in IP or those that did not.; some of the reported dislikes may represent real experiences of the IP, others may represent what participants thought it would be like.

The review of this literature shows a variety of positive outcomes for *plwd* and pre-school children, however IP activities may not be for everyone in these groups. In the studies reviewed some children chose not to join in IG activities. Feedback from a small number of older adults and their caregives indicated that noise, and comotion, for example were factors that older adults living with dementia not like. In one study some *plwd* experienced an increase in fear/anxiety in sessions with children, albeit a very small increase (Camp et al., 2004).

When comparing the findings from these studies, several factors are important to consider. IG interventions involve many factors and their influence in shaping positive outcomes may be difficult to isolate. For example, the experience of the ‘experimental group’ in the Camp and colleague series of studies (Camp et al, 1997; Camp et al., 2004; Lee et al., 2007) differed from the experience of the control group in at least two ways; children were involved, and Montessori based activities, therefore it is difficult to identify which element resulted in the benefits. The studies completed by Newman and colleagues (Newman & Ward, 1992-1993; Ward et al., 1996), and Camp and colleagues (1997, 2004; Lee et al., 2007) were evaluated using purely observational data ; *plwd* were not asked to report on their experience.

Table 2 : *IP interventions involving plwd and pre-school children*

Authors and country	Activity, context and underpinning theory	Duration	Participants	Study design	Measures used
Camp et al. (1997) USA	Montessori Based activities completed in a special care unit in a nursing home	Once a week for 30-45 minutes. More than 75 sessions were completed	9 older adults with dementia (from 70-96) 8 Children aged from 2.5-4 years old.	Adults only: Observational: Pre-test post-test. 5-minute observations were taken before, during, and after each session.	Apathy; 'sleeping or staring into space for more than 10 seconds' Successful teaching: activity which had been presented to the child is completed by them.
Camp et al. (2004) USA	Montessori-based activities at a day care centre on SSIP	20 mins twice a week for a year.	15 older adults Age 50-95 (M=80.57) and 13 children aged 2.5-5 years	Adults only: Observational: Pre-test post-test using a control group. Observations were completed on *plwd* using 5 min timeframes, before, during and after each Montessori session The Affect Rating Scale was completed after each observation	Two for *plwd*: 1. Myers Research Institute Engagement Scale (MRI-ES) Designed by authors 2. Affect Rating scale measuring pleasure, anxiety/fear and sadness.
Jarrott and Bruno (2003) USA These two papers relate to one case study	A shared site IP programme 'One Generation'; providing day care for children aged 6 weeks to 6 years and older adults (average age 78.5), 87% with Alzheimer's or cognitive impairment. Typical activities included: sharing meals and snacks, collage, bingo, making bread, music and movement. The older adults either watched children, collaborated on activities with them, or mentored them. *Kitwood (1997), Allport (1954), Pettigrew (1998)*	Ongoing: Children typically attend 5 days a week, older adults 3.5 days a week.	48 *plwd*, 21 were nvolved in IP. Average age 70 average MMSE 16.5.	Observational with control group 4-5 *plwd* were observed over a 5-day period of for 6 hours per day.	DCM
Jarrott and Bruno (2007) USA		Adults have 7 opportunities for IP daily.	39 *plwd*, 50 caregivers of older adults living with dementia and 24 carers of children aged 1-4.	*Plwd* engaged in 10–15-minute interviews. Parents and carers completed 21 item surveys.	Open ended questions explored likes/dislikes Designed by researchers

Authors and country	**Activity, context and underpinning theory**	**Duration**	**Participants**	**Study design**	**Measures used**
Lee et al. (2007)	Montessori-based activities at a nursing home	Twice a week for 20 mins for a year (6 months each group: While one was engaged in IG activities other group acted as control.	14 nursing home residents on dementia special care unit at skilled nursing facility., aged 85-94 M=90.20. 15 children from onsite day care facility for children of staff: aged 2.5-5 years	Adults only: Observations on *plwd* at three time points twice a week for a year: 5 mins, before, during and after each Montessori session	Myers Research Institute Engagement Scale (MRI-ES) which measures 5 types of engagement: constructive (motor or verbal relating to IG activity), passive (listening or looking), active (Listening or looking unrelated to IG activity), self (listening or looking related to themselves, picking at buttons for example), non (lack of attention).
McNair and Moore (2010) USA	Care home in SSIP	Two visits a week: 1: 15mins 'friendly' visit 2: 45 mins reminiscence, totalling an hour a week *for 8 weeks.*	27 residents 12 pre- kindergarten children. The ages of the children were not stated.	An observational study with control groups of adults and children. Adults: Observation during the intervention plus one question post intervention Children: assessed post intervention	Adults: Observational protocol designed by researchers, plus one question post intervention: 'How did you feel about your visits with the kids'? Children: Pictorial: 'Draw a picture of an old person like a grandma or grandpa' Verbal: 'can you tell me about old people like grandmas and grandpas
Newman and Ward (1992-1993)	Music and movement in an adult day care	Session length: 30 mins with children, 30 mins without. Intervention length: once a week for 5 weeks	21 adults with 'behavioural symptoms of dementia' and 20 4- & 5-year-old children	Adults only: Observation: sessions were videotaped. A control group was used.	An observational protocol was designed by researchers looking for: eye contact, smiling, rhythmic hand movement, verbal expression, touching, extending hands, head nodding & laughing.
Ward et al. (1996)	Music and movement in a residential care home	Session length:30 mins without children then 30 mins with	24 older adults with Dementia 66- 95 and 24 children from 6 months to 5 years	Adults only: Observational on *plwd*: Positive behaviours and agitation. A control group was used	An observational protocol was designed by researchers looking for: eye contact, smiling, rhythmic hand movement, verbal

Authors and country	Activity, context and underpinning theory	Duration	Participants	Study design	Measures used
		Intervention length: 6 months This study represents 6 weeks of data as researchers deemed this sufficient to evaluate the intervention			expression, touching, extending hands, head nodding & laughing. Cohen Mansfield agitation inventory completed by nursing assistants who were interviewed twice a week.

3.3 FINDINGS-IP INVOLVING SCHOOL CHILDREN

Three studies reviewed in this section, and presented in Table 3, were completed in the USA, the fourth was completed in England. Activities included reading, writing, singing, reminiscence, and life history. Activity sessions typically lasted about 45 minutes to an hour; the duration of the programmes ranged from 8 weeks to 5 months.

Study design: The RCT was the only intervention which involved a control group (George, 2011; George & Singer, 2011). To assess the outcomes for *plwd* observations and psychometric tests, (McNair & Moore, 2010; Di Bona & Kennedy, 2017), plus interviews (George, 2011) were used.

All studies evaluated outcomes for adults, two assessed outcomes for children. Di Bona et al. (2015, 2017) completed interviews with teachers, care home managers and care home staff involved in the project, George and Singer (2011) completed interviews with caregivers, family and staff.

Outcomes for older adults: No significant findings were obtained from psychometric measures used by Isaki and Harman (2015). George (2011) found no significant differences between the experimental and control group in four of five factors; decline in cognitive function, decline in depression, or increase in sense of purpose or sense of usefulness. However, a significant decline in stress in the IG experimental group was found. By pooling all of the qualitative data George (2011, p.991) identified three 'broad meta-categories' representing how IP had affected the quality of life of participants; perceived health benefits, sense of purpose & usefulness, and relationships. Data indicated that participants had experienced health benefits, a sense of purpose and usefulness, and accepting relationships with children. Di Bona et al. (2015, 2017) observed many instances of residents who had bright eyes and smiling faces, and no instances of distress or agitation to the extent that participants left the intervention. Additional observations indicated that interventions had been mutually enjoyable for both groups of participants (Di Bona et al., 2017; Isaki & Harman, 2015).

Outcomes for children: Di Bona et al. (2015, 2017) found some improvements to the children's knowledge of dementia; however, the children had started with little knowledge about dementia, and their knowledge remained limited after the intervention. Isaki and Harman (2015) found that the children's perceptions of older adults improved. Di Bona et al. (2015, 2017) also found the children's experiences of the intervention were mixed. Many of the children stated that they had been worried before meeting the residents with dementia, particularly that they might become ‘angry and frightened, especially if they were asked something that they did not understand’ (Di Bona et al., 2017, p.7), however most were pleased that they had been involved in the project. A few were ‘not bothered either way’ (Di Bona & Kennedy, 2015, p.29) and one child said that they ‘preferred the lessons to the care home visits’ (Di Bona & Kennedy, 2015, p.29).

The ‘adopt a care home’ study (Di Bona et al., 2017) was the first of this kind to be published in the UK and provided interesting insights to implementing and evaluating IG interventions, but had some limitations. The evaluation was brief and pragmatic and did not aim to gain an in depth understanding of the experiences and effects on all participants. Many of the results were general and lacking in detail, for example discussing ‘most children’, however the report provides a clearly written, extensive account, of the project. The evaluation highlighted challenges faced by an evaluation of an IG intervention due to time constraints on teachers and children, care home staff and residents. The focus group for children for example was too big, and the observations were sometimes too short. Two members of the care home staff were interviewed together, and some of the interviews were not audio recorded and transcribed, researchers simply made notes of the interviews. All of these factors affected the reliability and validity of the results however they illustrate some of the challenges inherent in such evaluations. The researchers made some valuable recommendations regarding future similar research, they suggested the creation of a resource pack that teachers could use in future interventions, they suggested that a designated individual be appointed to organise and facilitate contact with residents with dementia and school children, and that the experience of residents with dementia should be assessed by asking the residents, as opposed to the carers.

Table 3: *IP interventions involving plwd and school children*

Authors and country	Activity, context and underpinning theory	Duration	Participants	Study design	Research tools
Di Bona et al. (2017) UK	Dementia education in a care home	A year group receiving one school term of lessons on dementia.	41 children aged 9 or 10 visited the care home. 10 *plwd* aged between 70 and 90. 8 school care home staff	Case study Children: completed pre-test-post-test questionnaires, and focus groups post IP Adults: observation during IP Staff: post IP	Children: Dementia awareness questionnaire (Alzheimer's Society 2014b) Adults: protocol devised by researchers Staff: semi-structured interviews
George (2011) USA	Two interventions were included: 1. With children (aged 5-6) singing, small group reading & writing **2.** With children 11-14 IG life history, reminiscence in a care home	Approximately an hour a week for 20 weeks	15 adults over 50 with mild to moderate dementia. No details were provided for children	Adults only: an RCT with a control group; repeated measures, pre-test, post-test	1: MMSE,2: Beck anxiety inventory, 3: Beck Depression Inventory, 4: sense of purpose questionnaire 5: sense of usefulness questionnaire
George and Singel (2011) USA	As above	As above	As above	As above Data collected from caregivers, family & staff	Structured and unstructured interviews
Isaki and Harmon (2015) USA	Reading in an assisted living facility	45 mins weekly for 8 weeks	6 adults with mild dementia 12 children 8-11 with language or reading concerns.	Adults only: A repeated measures within group, pre-test, post-test design. Pre and post every session	Adult: MMSE Mood and communication questionnaire developed by researchers Children: Chidrens' views on Aging (CVOA) (Newman & Marks, 1997)

Authors and country	Activity, context and underpinning theory	Duration	Participants	Study design	Research tools
McNair and Moore (2010) USA	Maths, science, IT, language, reading, baking. Completed in a care home in SSIP however half of sessions were delivered at community school	1 hour a week for 6 weeks	12 residents living with dementia 17 adolescents between 13 & 15. 9 of these students had ‘special needs’	Adults were observed during intervention and ‘other’ time. They also completed an interview post intervention Adolescents completed a questionnaire pre-test, post-test, and a questionnaire about feelings post test	Adults: Comprehensive Evaluation in recreation Therapy (CERT) Interviews post intervention Adolescents: Children’s views on aging (CVOA) (Newman & Marks, 1997)

3.4 INTERVENTION DESIGN FACTORS WHICH MAKE A DIFFERENCE

A number of programme elements were identified as being essential considerations for successful interventions, including; the duration of the intervention, group size and structure, staff involvement, facilitating the activities, and support provided for students.

3.4.1 Duration of the intervention

The duration of IP programmes reviewed ranged from a one-hour long poetry workshop (Garrie et al., 2016), to two 20-minute visits a week for a year (Camp et al., 2004). Individual activity sessions generally ranged from 20 minutes (Camp et al., 2004) to 90 minutes (Chung, 2008; George et al., 2013; 2014; Harris & Caporella, 2014; 2018; Lokon et al., 2012); although student visits in one study lasted 3 hours (Wood et al., 2017). Many of the sessions lasted between 45 minutes to an hour (George, 2011; Isaki & Harmon, 2015; McNair & Moore, 2010; Sauer et al., 2014; Ward et al., 1996).

Increases in positive attitudes towards dementia, and improvements in the engagement of *plwd* were reported in short IP programmes. Garrie et al. (2016) found significant improvement in student scores on the DAS (O’Connor & McFadden, 2010) after an hour-long poetry workshop, George et al. (2013, 2014) reported increases in student scores on the DAS (O’Connor & McFadden, 2010) after 4 weekly storytelling sessions. Newman and Ward (1992-1993) found an increase in touching and extending hands amongst older adults during a 5-week music and movement programme.

After a programme which lasted an hour a week for 20 weeks George (2011) suggested that: more studies should be completed with higher ‘dosage’ however Chung (2009) found that students and older adults living with dementia found a 12-week programme involving 1 session a week, challenging. Whilst most student responses about the programme were positive, negative comments about the length of the intervention, and workload were gathered.

Based on the literature, activity sessions in the current intervention were completed once a week for four weeks, and planned to last between 45 minutes and an hour. There was a reasonable expectation of change in student attitudes towards dementia, and the engagement of *plwd* in the current study, as this has been reported in previous short programmes (Garrie et al., 2016, Newman & Ward, 1992-1993).

3.4.2 Group size and structure

The group sizes typically varied from six to 39: Lee et al. (2007) included two to five 'dyads', whilst Harris and Caporella (2014, 2018) included up to 39 people weekly: 13 students, 13 *plwd* and 13 family members. Whilst larger groups may be practical for some activities such as choir practice Di Bona and Kennedy (2015) found smaller groups to be advantageous. Their intervention involved 10 residents living with dementia and 16 children working together to complete mini life story booklets. During the first visit to the care home all participants completed the intervention in one room which care home managers and staff deemed; 'too big' and 'too noisy'; staff also felt that it may have negatively impacted the residents' ability to engage.

Participants completed activities in pairs during many of the IP interventions reviewed (Camp et al., 1997; Camp et al., 2004; George & Singel, 2011; Gigliotti et al., 2005; Harris & Caporella, 2014; Lee et al., 2007; Lokon et al., 2014; Lokon et al., 2017; Sauer et al., 2014). A 1:1 approach is recommended for IG interventions by Lokon et al. (2016, p.471) who compared 5 activities for *plwd* and concluded that the nature of the activity did not appear to make a difference to study outcomes but that' to create significant improvement in their wellbeing, *plwd* need well-designed activities with 1:1 ratio between *plwd* and well-trained volunteer volunteers/staff member's'

Based on the literature, a group size of no more than 8 participants was agreed with care home managers for the current intervention. A one-to-one design was planned with 2-3 pairs on a table. The researcher considered that this design would provide good support for *plwd*, would enable relationships to develop (Harris & Caporela, 2014, 2018; Sauer et al., 2014) and would not be overwhelming for *plwd*. It is possible that the 1:1 design is a factor which distinguishes IP programmes from other activities; it may be that the 1:1 focus is actually the component that makes a difference to study outcome. To correct for this possibility the control and experimental conditions in the current study were both designed to involve pairings; during the control intervention *plwd* were paired with a resident without dementia, during the IG intervention *plwd* were paired with a student volunteer.

3.4.3 Involvement of staff, professionals and the research team

The role of care home staff was attributed, in part, to the success of a number of the programmes in care homes (Di Bona et al., 2017; Newman & Ward, 1992-1993). Chung (2009) attributed the low dropout rate of participants to the on-going support and encouragement provided by staff.

However, the role of staff differed; in the programme completed by Jarrott and Bruno (2003) staff were present whilst adults acted as mentors. In the study completed by Di Bona et al. (2017, p.11) staff provided safeguarding and support, and input to re-engage *plwd* who became disengaged, however this was not always successful*'*. In programmes completed by George (2011), Di Bona et al. (2017), and Ward et al. (1996) staff acted as activity facilitators, whilst trained programme facilitators delivered the Opening Minds through Art (OMA) and Timeslips programmes (George et al., 2013; 2014; Lokon et al., 2012; Lokon et al., 2017; Sauer et al., 2014).

Based on the literature, the role of care home staff in the current intervention was based on safeguarding and supporting participants. The role of care was to predominately observe and ensure that the activities were running smoothly, as in the study completed by Di Bona (2017). Staff were present to offer support and encouragement, and help residents and students if they experienced difficulties with the activities, or appeared anxious or distressed. An activities facilitator was planned for the research team to demonstrate and lead the activity sessions, as in previous studies (George et al., 2013; 2014; Lokon et al., 2012; Lokon et al., 2017; Sauer et al., 2014), to ensure consistency across both homes, and keep demands on staff time to a minimum. The procedure undertaken to appoint and train the activities facilitator is discussed in Chapter 5. The role of the researcher was to have 'as little input as possible' as in the study completed by Camp et al. (2004)

3.4.4 Support for students

The studies reviewed here involving students indicated that good support is essential. Student feedback on the intervention process was mixed. Students reported experiencing fun and enjoyment during some interventions (George et al., 2014; Lambert-Shute et al., 2004; Lokon et al., 2012), but challenges were experienced too. Orientations were considered helpful, but some students reported a lack of guidance from site staff (Lambert-Shute et al., 2004), particularly on the first visit, and poor communication amongst staff (Wood et al., 2017). Some students experienced challenges around residents becoming upset, ‘mood fluctuations’ and deciding whether to help residents’ complete tasks, or let them complete tasks independently (Yamashita et al., 2011). Although support was provided by a facilitator in the intervention implemented by Lamburt-Shute et al. (2004) a number of students found their lack of availability challenging. The amount of time that students dedicated to the intervention was challenging: a scrapbook task was cited as ‘hard to fit in’, and conflicted with other activities (Lambert-Shute et al., 2004), and the length of a reminiscence intervention was experienced as challenging to accommodate in their workload (Chung, 2009).

Based on the literature, all students attended an information event where the project was outlined to them, and they were able to ask any questions and raise any concerns that they had. The care home provided an induction prior to the start of the intervention, and staff and the research team were available for support the whole time. Students were never left alone within the care home.

3.4.5 Underpinning Theory

Few of the studies in the literature review discussed earlier in this chapter explicitly discussed theoretical foundations, in fact personhood (Kitwood, 1997) and contact theory (Allport, 1954; Pettigrew, 1998) were the only theories cited. Kitwood’s theories were used to develop the ‘opening minds through art’ programme which formed the basis of IG interventions (Lokon et al., 2012; Lokon et al., 2017; Sauer et al.; 2014). Contact theory (Allport, 1954; Pettigrew, 1998) formed the basis of IG interventions, which aimed to change the attitudes of students towards *plwd* (Harris & Caporella, 2014; 2018). A combination of both theories was used in evaluations of the ‘one-generation’ SSIP which explored outcomes for children and older adults living with dementia (Jarrott & Bruno, 2003; 2007).

Personhood (Kitwood, 1997) and contact theory (Allport, 1954; Pettigrew 1998) were considered most appropriate for this thesis as they support the intended outcomes of the intervention; enhanced wellbeing of *plwd,* and improved attitudes towards *plwd* amongst students. The theories complement each other as they both focus on; relationship, collaboration, a supportive environment, and inclusion.

3.5 THE THEORETICAL FOUNDATIONS OF THE THESIS

3.5.1 The use of theory in this thesis

Kitwood's philosophy of care (1997) and contact theory (Allport, 1954; Pettigrew, 1998) underpinned the intervention design and delivery, plus the interpretation of the outcomes for *plwd* and students. The theories are critically appraised in the following sections, alongside the way in which they were incorporated into the intervention design. The way that they underpinned the interpretation of results is discussed in Chapters 7 and 8.

3.5.2 Kitwood's key concepts

Tom Kitwood was one of the most influential writers on the experience of dementia (Baldwin & Capstick, 2007). His work was based on a number of key concepts; he challenged the medical model of dementia (1989, 1997) and proposed an 'enriched model of dementia', described wellbeing and illbeing relating to *plwd*, and identified actions of carers that impacted both. Kitwood and Bredin (1992) proposed a model of dementia care based on maintaining personhood. In 1997 Kitwood described five psychosocial needs experienced by *plwd*, and suggested that meeting these needs will maintain personhood and result in relative wellbeing. These philosophies underpin Positive Person Work (PPW) (1997), and person-centred care. The following sections will describe each of these concepts in more detail.

3.5.2.1 An enriched model of dementia

Kitwood (1989) suggested that the 'standard paradigm' was insufficient to account for all symptoms of dementia (AD), and was highly critical of the medical conceptualisation of dementia which dominated until late in the 1980s. He challenged the robustness of post mortem evidence which illustrated correlations between the degree of dementia exhibited by people living with the condition, and the extent of neuropathic damage, arguing that the correlations were 'rather low' (Kitwood, 1989, p.13). He offered an alternative explanation that the brain damage found at post mortem is not a cause of the condition, but as a consequence. Hughes (2019) acknowledges that many of the claims that Kitwood makes about 'dementia as a psychiatric category' are accurate, however highlights a number of inaccuracies. For example, Hughes (2019) questions the number of cases that Kitwood (1989) cited, in which there was no correlation between symptomology and biology in post mortems, and Kitwood ‘s incorrect use of ‘the medical model’. Hughes (2019, p.40) argues that many medics take a broader view than that which Kitwood (1989) described, which was essentially the ‘disease model’ (Hughes, 2019, p.40).

Kitwood (1990, p.180) proposed a new dialectical framework for dementia (**Senile Dementia = Neurological Impairment + Malignant Social Psychology**). He likened the attitudes and actions of individuals that disempower people living with dementia to the social model of disability and made this a focus of his research, in which he observed *plwd* in the care setting. He made notes of ‘incidents’, which he classified later (Kitwood, 1990b), naming them as Malignant Social Psychology (see Appendix 2 for a list and description of these interactions). The word malignant did not suggest intentional, rather he suggested that these behaviours were prompted by kindness, but nevertheless were deeply damaging to personhood. He suggests reasons for MSP from carers which include that; they are: busy, and that being with a person with dementia ‘is to be close to one of their most pressing fears’ (p.186). Kitwood, (1990, p.193) acknowledges that his theory is ‘so ill-defined that it is immune from the kind of rigorous testing that might falsify).

Kitwood posited that the manifestation of dementia should be understood as comprising of five key factors: **Dementia = Personality + Biography + Physical Health + Neurological Impairment + Social Psychology**., which aligns with the bps model of ill health proposed by Engel (1977), which takes account of biological, psychological and social aspects of illness. Three of the factors are fixed; biography, personality, and neurological impairment, however Health and Social Psychology are open to great change (Kitwood, 1997b).

3.5.2.2 Relative wellbeing experienced by people living with dementia

Plwd experience cognitive impairment which may be accompanied by anxiety, depression, and apathy, therefore Kitwood and Bredin (1992, p.280) state that it is sensible to discuss ‘relative wellbeing or illbeing’ ‘in a way that cuts across the dimension of cognitive impairment’. According to Kitwood and Bredin (1992) there are 12 indicators of ‘relative wellbeing’ which can be observed in *plwd*, which are expressions of four global states: 1) a sense of personal worth, 2) a sense of agency, 3) social confidence, 4) hope. The 12 observable indicators are illustrated in Table 4 alongside indicators of illbeing as described by The University of Bradford (2016, p.25).

Table 4: *Indicators of wellbeing and illbeing amongst people living with dementia*

Indicators of wellbeing	Indicators of illbeing
Assertiveness	Unattended despair
The ability to experience a range of emotion	Intense anger
Initiating social contact	Unattended grief
Affectional warmth,	Anxiety
Social sensitivity (empathy),	Fear
Self-respect,	Boredom
Acceptance of others living with dementia	Physical discomfort
Humour,	Bodily tension
Creativity and self-expression	Agitation
Showing pleasure	Apathy
Helpfulness	Withdrawal
Relaxation.	Cultural alienation
	Difficulty withstanding powerful others

N: B The contents of this table are taken from Kitwood (1997b) and UOB (2016)

3.5.2.3 Personhood as a basis for person centred care

Kitwood and Bredin (1992, p.269) proposed a social-psychological theory of dementia care in which the main aim is to maintain the 'personhood' of the *plwd*. Personhood was conceptualised as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being...implying recognition, respect and trust, of the individual with dementia throughout their life course' There is debate in the literature about the meaning of personhood; for example, Dewing (2019) acknowledges that Kitwood advanced person-centred care but argues that personhood is not a gift to bestow, and that suggesting that one person bestows it on another indicates separation.

Kitwood (1997a, p.19) discusses five psychosocial 'needs' 'that without which a human being cannot function, even minimally, as a person', and states that all human beings have these needs but that they are evident in *plwd*. If the care provided meets all of these psychological needs, over time therapeutic change will occur. The five needs are attachment, comfort, identity, occupation and inclusion are closely intertwined and represent one overall need for love.

According to Kitwood (1997a, p.19) attachment describes a need to form bonds that, 'create a kind of safety net […] when the world is full of uncertainty'. A need for attachment in *plwd* may be as strong as Bowlby (1958) suggested that it is in childhood, but attachment needs may be invoked in *plwd* as they constantly face new situations. Kitwood (1997a, p.20) stated that: 'to be occupied means to be involved in the process of life in a way that is personally significant, whether this consists of action, reflection, or relaxation'. To have an identity means that people have a past, a narrative of their life to share with others. Identity is, in part, 'conferred by others, as they provide subtle messages 'about his or her performance' (Kitwood 1997a, p.20) especially so for *plwd* whose cognition decreases and they rely on others to scaffold/present their story/identity. Kitwood says that two things are essential to maintain identity; i) knowing, in some detail, an individual's life history and ii) responding to a person as unique (Brooker & Kitwood, 2019). According to Kitwood inclusion is a basic human need; he states that being part of a group was on an evolutionary basis essential for survival, and that exclusion can be used in some groups as a form of punishment. In traditional long-term care *plwd* were 'left together but profoundly alone' (Brooker & Kitwood, 2019, p.94). Comfort is a soothing, calming experience, one in which the individual feels secure Brooker & Kitwood (2019, p.94). Comfort typically comes from closeness with others (Brooker, 2019, p.93). Kitwood suggests that *plwd* have a need to feel 'thoroughly strong', and that comfort enables a person; 'to remain in one piece when they are in danger of falling apart (Kitwood, 1997, p.19). Table 5 outlines manifestation of the needs, positive person work interactions and Malignant social psychology interactions that are linked to the needs, and the impact of these interactions on the wellbeing of *plwd*.

Kitwood (1997) states that the needs are interlinked and that one affects another. If the *plwd* is comfortable they are more likely to make attachments, have more attention to engage in occupation, less time for anxiety and fear. Occupation will feed into identity, and that; ‘many kinds of virtuous circles can be envisaged’ As the whole set of needs are met there is likely to be a global increase in self-worth and a feeling of being valued and valuable, which will result in wellbeing.

Table 5*: Manifestations of psychosocial needs and interactions that meet or undermine them*

Psychosocial Need	Manifestation of need	Met through PPW	Result of Meeting the need	Undermined by Malignant social Psychology	Result of unmet need
Attachment		Acknowledgement Genuineness Validation		Accusation Treachery Invalidation	
Occupation	Wanting to help, eagerly take part in activities	Empowerment Facilitation Enabling Collaboration		Disempowerment Imposition Disruption Objectification	Loss of self-esteem, abilities atrophy, boredom, apathy, futility
Inclusion		Recognition Including Belonging Fun	A sense of belonging. *Plwd* can 'expand again and take a distinct place in the group.	Stigmatisation Ignoring Banishment Mockery	Decline and retreat, possibly into vegetation
Identity	'Attention seeking, clinging, hovering, protest and disruption (Kitwood 1997, p.94)	Respect Acceptance Celebration		Infantilisation Labelling Disparagement	
Comfort	Heightened sexual desire for some *plwd*	Warmth Holding Relaxed Pace	Increased sense of security, decrease in anxiety	Intimidation Withholding Outpacing **N.B:** all MSP damage self-esteem and diminish personhood	

The contents of this table are taken from the work of Kitwood (1989,1990,1993, 1997a, 1997b) and UOB (2016)

Whilst innovative at the time, Kitwood's (1990) work was not clearly based on a substantial body of empirical evidence. Rather, he drew on psycho-biographies of individuals who had developed dementia, extended semi-structured interviews with one or more family members' (Kitwood, 1990, p.178), and his own close involvement with and observation of *plwd*. He recognises the empirical weakness of the theory he proposed: '(the theory is) so ill-defined that it is immune from the kind of rigorous testing that might falsify it' (Kitwood, 1990, p.193). Over the course of time as his ideas evolved, he also shows his own ambivalence about the research methods that he used (Kitwood, 1993), calling his research method 'ethological' because it involved very detailed case studies of *plwd* and 'miniature interventions' in 'their own settings' (care homes, day centres, and their own homes). It is clear therefore, and by his own admission, that Kitwood's (1990) ideas were not borne from rigorous empirical analysis and methodological rigour. As Baldwin and Capstick (2007) argue however, at the outset of any theory there have to be ideas/theories to test and it is clear from the evolution of his writing that Kitwood's ideas changed across time.

There has been support for person centred care. Brooker (2019, p.18) states that despite the challenges of 'developing a robust evidence base for person-centred care, that by its definition is tailored to individual need and contextual relationships is a major challenge' there is now evidence of the effectiveness of person-centred care approaches for *plwd* in care homes. Kaufmann and Engel (2014) examined Kitwood's 'model of psychological needs and wellbeing' by conducting interviews with 19 residents living with moderate or severe dementia residing in a care home in Germany. The researchers used content analysis to generate 30 descriptive components which were grouped into the five domains named by Kitwood. Their findings offered empirical support for Kiwood's five domains; however, they found some differences between the definitions and the experiences of *plwd*, and suggested some extensions to the theory, most notably the addition of agency as a domain. Johnstone and Narayanasamy (2016) found that few interventions have tested Kitwood's framework, and suggest that more should do so.

Brooker (2019) states that Kitwood's theories have stood the test of time, and that evidence supporting them is growing, however putting them into practice has been slow. There has not been the desired shift, and that poor care/practice is still the experience for many. With limited resources, low skills and staffing levels, plus greater need and complexity of needs acting as barriers, ‘person centred care is seen as the unreachable ideal’ (Brooker, 2019, p.82). Cheston (2019) agrees that there have been many advances in dementia care which is now high in public consciousness and discourse however with monetary constraints still being a big issue, there are many *plwd* still experiencing traditional care which Kitwood described as poor.

In sum, Kitwood’s contribution to the field of dementia care and research has been to encourage us to focus attention on the social aspect of dementia, with his notion of person-centred care drawing on recognised theorists like Carl Rogers (1961), and highlighting the shortcomings of malignant social psychology. He emphasised the role of social interactions for *plwd*, identified negative interactions which could be harmful to *plwd*, and positive social interactions which could be therapeutic in their effects. There is however clear evidence that his ideas have influenced dementia care. Person-centred care places the individual *plwd* at the centre of care planning and provisions is now the recommended model of care for *plwd* which is reflected in the statutory guidance (NICE, 2018).

3.5.3 **Contact Theory (Allport, 1954, Pettigrew, 1998)**

Prejudice was described by Allport (1954, p.7) as: ‘a feeling, favourable or unfavourable, toward a person or thing, prior to, or not based on, actual experience’ who proposed contact theory (Allport, 1954) as a way to address it. Allport (1954) linked causes of prejudice to thought processes, for example, the creation of stereotypes as a cognitive shortcut. Allport (1954, p. 187) suggests that ‘a stereotype is an exaggerated belief associated with a category’, and that they also have the function of simplifying the amount of information that we need to process. Subjectively however ‘the possession of stereotypes may interfere with even the simplest rational judgements’ (Allport, 1954, p.193).

Allport (1954) suggested a number of ways to bring about attitude change and subsequently address prejudice including legislative reform, challenging segregation, using formal education programmes, as well as contact and acquaintance programmes which bring groups together, and group retraining methods using group and individual therapy approaches. Whilst the optimum method may be a combination of approaches, the most researched approach is that of contact programmes.

Allport (1954) argued that contact alone may be insufficient to change attitudes and indeed that contact alone may increase stereotyping, as people approach any interactions with preformed ideas which may affect any interactions that they have with that group. He proposes that bringing two groups of people into contact with each other will reduce prejudice, provided 4 conditions are in place: (i) groups should have equal status during contact; (ii) groups should work towards shared goals; (iii), contact between the groups should be regular enough and long enough to develop true acquaintance; (iv) and contact should be facilitated in a supportive, normative environment.

Allport's (1954) influential seminal work has been tested extensively since its conception. Although the contact theory was originally created in an American context for use with interracial prejudice, in a meta-analysis of over 500 journal articles published over 50 years later, Pettigrew and Tropp (2006) conclude that the theory can be generalised to other groups, and is effective in reducing stereotypes, and thus in reducing negative or stereotyped attitudes.

Pettigrew (1997) completed a study involving survey data from 3,806 respondents across 4 Western nations (France, the Netherlands, the UK and West Germany) and study populations of Turkish immigrants in West Germany; North Africans and Asians in France; Surinamers and Turks in the Netherlands; and West Indians and Asians in the UK, highlighted the role of emotions as a mediating process underpinning change in attitudes as a result of contact. Although this study was cross sectional and self–report, the size of the populations surveyed mean that a clear association could be drawn between the role of feelings/friendship, and contact as a mediating factor. Whilst previous researchers focussed on assessing the effect of learning about members of the 'out group' on the cognitive process, which had shown its effect in reducing stereotypical views and prejudice, Pettigrew also highlighted the role of empathy and identification, concluding that 'optimal intergroup contact requires time', and that 'only longitudinal studies…can adequately study the mediating process of the phenomenon' (1997, p.182). Pettigrew later (1998) added an additional tenet that 'the contact situation must provide the participants with the opportunity to become friends' (Pettigrew, 1998, p.76) in order for intergroup contact to be effective.

Contact theory (Allport, 1954) has recently informed the conceptual framework for IG studies involving people with dementia (Caspi, 1984; Harris & Caporella, 2014; Teater, 2016; Jarrott & Smith, 2010). Caspi (1984) was the first to use the contact theory as a framework for IG interventions, undertaking a cross sectional study comparing the ability of children (aged between 3 and 6) from a traditional child care facility with children from a child care facility where staff were generally over 60 to differentiate between the ages of older adults. Caspi presented the children with pictures of older adults and asked them to place the pictures in order according to their age; the children from the IG group were more accurate on this task; they also held more favourable attitudes towards older adults than the children who attended the traditional child care centre.

The study's findings are important because they indicate that IG contact increases awareness of, and comfort with older adults amongst children but crucially, it does not satisfy one of the central tenets of Allport's (1954) contact theory, that is, that participant groups did not hold equal status in the situation. The author concluded that the older adults were given higher status than they would normally be given, and warned that 'if cross-age contact were to occur in a nursing home with feeble elderly it would probably serve to foster stereotypes' (Caspi, 1984, p.79).

Teater (2016) interviewed 12 children aged 11-12 about their experience of IG, and found that two tenets of the contact hypothesis; 'equal status' and 'common goals', were important in IG interventions. The artwork which was the common goal in this study acted initially as a 'distractor' as the children said that they would have found it difficult to spend time with the older adults in the early stages of the programme without anything to do. As the programme progressed the artwork acted as a mediator; providing a shared interest which formed the basis of conversations which drew the participants together. Teater (2016) suggests that future research should explore the nature of the 'common goal', for example is it the specific task that brings people together or would any task produce similar results?

In sum, Allport (1954) suggested that prejudice could be addressed with social contact between groups based on 4 conditions; groups have equal status, work towards shared goals, have contact which is regular enough and long enough to develop true acquaintance, and contact is in a supportive, normative environment. Pettigrew (1998, p.76) added a fifth tenet; ‘the contact situation must provide the participants with the opportunity to become friends. Contact theory has been tested widely and has extended to IG interventions. IG interventions based on this theory are most likely to achieve their goals. Using the contact theory (Allport, 1954) the current study will explore whether personal contact between group members, older people living with dementia and students, is effective in allowing individuals to see different perspectives, therefore improving attitudes and reducing stereotyping.

3.5.4 Critical appraisal of the theories of Kitwood and Allport

In choosing to use the work of Kitwood, Allport and Pettigrew as the theoretical foundations of the thesis, this does not mean that they are without their shortcomings. The follow sections (pp. 67-78) therefore offer critical reflection both of their limitations as theories in the study of the needs of *plwd* within a care context, and intergroup contact.

3.5.4.1 Shortcomings of Kitwood’s theories

The following section discusses three shortcomings of Kitwood’s original framework. Firstly: a lack of rigorous exploration of the concepts of needs and their components and the challenges this poses for those using his framework; secondly: exclusion of the notion of agency, and potentially citizenship, as relevant to wellbeing and personhood for *plwd,* and thirdly: overlaps in the concepts of needs.

The first shortcoming to Kitwood’s work which must be acknowledged is his failure to engage in philosophical debate about the nature of wellbeing in terms of a rigorous conceptualisation and empirical measurement of the core elements of his personhood and wellbeing framework (Baldwin & Capstick, 2007). His contributions to the field, although highly significant, are not founded upon a rigorous, coherent and empirically validated conceptual framework. For example, there is limited attempt to conceptualise the 5 elements of wellbeing, which Kitwood described as needs: occupation, identity, inclusion, attachment, and comfort. Kitwood argued that if all these five needs are met, then personhood is maintained, which results in wellbeing. However, lack of conceptual clarify about these 5 needs means they are open to differing interpretations.

A clear illustration of this is the work completed in 2014 by Kaufmann and Engel who evaluated Kitwood's framework and found empirical support for each of these needs, whilst also elaborating them further by identifying different components to each and also including the notion of agency (see Table 6). They suggest that the need for agency contains three components: self-determination, freedom of action, and independence. The significance of autonomy and self-determination as being important to *plwd* was reinforced by Kristensen and Peoples (2020) who completed a meta-aggregation focusing on 10 qualitative studies based in long term care settings in Europe, The USA and Australia.

***Table 6**: Kitwood's needs and Kaufmann and Engel's additions*

Needs	**Components of the needs**
Attachment	People, Animals, Task, Anchor Items
Occupation	Idleness, Exercise, working, reading or listening to the radio
Inclusion	Community, Activity
Identity	Role maintenance, Recognition, lifestyle continuity, feeling healthy,
Comfort	Pleasure, Interaction, Positive Thoughts, Activity, Withdrawal, Positive feedback, spiritual rituals, altruism, comparison
Agency	*Self-determination, freedom of action, independence*

The limitations of Kitwood's initial conceptualisation of the needs of *plwd* is also illustrated through other authors who have found support for some of the components of needs identified by Kaufmann and Engel (2014). For example, O'Rourke's (2015) meta-analysis of 11 qualitative studies in community and long-term care settings in UK, USA, Canada, The Netherlands, Ireland, Australia and Japan, highlighted the importance of attachment to the immediate living environment and external surroundings, whereas Kitwood had focused only on attachment to humans.

It must also be said that Kitwood by his own admission, recognised the arbitrary and cross-cutting or overlapping nature of the needs he had identified, stating that: 'the boundaries are blurred', and 'come together as a central need for love' which he depicted as a flower (Brooker & Kitwood, 2019, p.92)

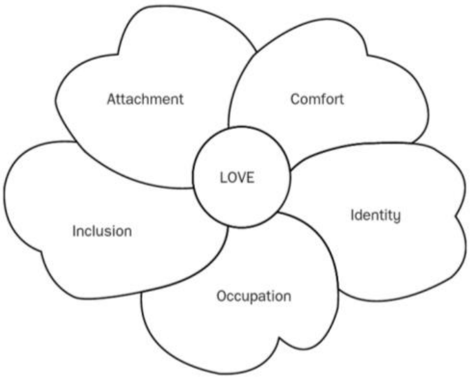

Figure 1: Tom Kitwood's representation of the 5 needs.

For the researcher, this overlap poses a challenge when trying to identify which need is being met in certain situations. Taking the example of conversation and communication, which can address a number of needs, for example, whilst Kauffman and Engel (2014) elaborated the components of Kitwood's need for occupation to include conversation and communication, they also coded 'contact with a high degree of emotion' as attachment.

In sum, critical appraisal of Kitwood's conceptual framework shows its inherent lack of conceptual clarity and an over-simplification of the different components of wellbeing and personhood for *plwd*. As illustrated here, the challenges of Kitwood's broad descriptions of the needs mean that it is open to individuals to decide what elements relate to each need. What these studies show is that the conceptual basis for this theory was not broad enough and that this conceptualisation of "needs" was quite elementary.

A second shortcoming of Kitwood's framework is that by conceptualising personhood as a phenomenon which relies on interdependency with others, his work overlooks any notion of the person living with dementia being able to exercise agency. This shortcoming is well illustrated through the work of Kontos based on self-embodiment.

Kontos and Naglie (2007, p801) agree with Kitwood that the focus of dementia care should be the maintenance of personhood but argue that: 'embodied selfhood emphasizes the corporeal nature of our being, which exists below the threshold of cognition and thus persists despite even severe cognitive impairment'. In an ethnographic study of selfhood amongst *plwd* in a Canadian long term care setting, Kontos (2004, p.832) identified four thematic categories; appearance, social etiquette, caring (displaying sensitivity to each other), dancing, and gestural communication (for example. winking, posture, direction and length of gaze, gaze avoidance, turning away) which they argue represent intentions and agency. In essence there is evidence to illustrate that people living with dementia can retain their personhood and agency, which challenges Kitwood's claim that other people are required to maintain the personhood of *plwd*.

As Kitwood's framework failed to take into account the notion of agency, his work did not extend to encompass the construct of citizenship, which itself embodies a recognition of agency (Bartlett, 2014). Using a citizenship lens, Bartlett and O'Connor (2010, p.12) stress the importance of 'seeing people with dementia as equal citizens with rights and sometimes responsibilities'; they therefore proposed extending Kitwood's (1997) needs with a broader conceptual framework reflecting the notion of citizenship (see Table 7). Whilst recognising a primal need for comfort they suggest that *plwd* should also have 'opportunities to grow' (growth), which incorporate creative opportunities. Bartlett and O'Connor (2010, p42) argue that: 'the notion of social positions is conceptually richer and more useful to a social citizenship framework than the notion of identity', because Kitwood's (1997) notion of identity fails to recognise multiple identities or roles that an individual has. It is important to recognise that a *plwd*, like others, has multiple identities which are likely to be of a higher status than 'someone living with dementia' which: 'routinely results in the downgrading of a person's status as an equal citizen' (Bartlett & O'Connor 2010, p.42). They posit that the term 'occupation' misses the importance of meaning attached to occupation, arguing that *plwd* want a sense of purpose, rather than simply occupation. This is pertinent for *plwd* as occupation is generally narrowly linked to psychosocial and therapeutic benefits, rather than everyday tasks. Bartlett and O'Connor (2010) also suggest that participation is a more active and appropriate term for inclusion, stating that people must be included, but that their inclusion must be recognised. Participation suggests involvement in action, as opposed to simply being present. Bartlett and O'Connor (2010, p.46) also question whether attachment is a purely emotional term, which they suggest should be extended to incorporate solidarity: 'Uniting with others to make a difference. Kitwood (1997) suggested that taken together, these five needs represent an overall need for love, however Bartlett and O'Connor (2010) warn that caring/loving relationships may manifest in control, and advocate the concept of 'freedom from discrimination' as a more powerful and appropriate term.

Table 7*: Extended continuum of concepts*

Kitwood's needs	Social Citizenship
comfort	growth
Identity	Social positions
Occupation	Purpose
Inclusion	Participation
Attachment	Solidarity
Love	Freedom from discrimination

To conclude, a critical appraisal of Kitwood's theories suggests that there are shortcomings in his work. Kitwood's theory of five needs laid the foundations for work in this field however the concepts were broad and were not defined precisely enough to provide a very strong empirical basis on which they could be tested. On a basic level, Kitwood's framework is valid, however the subsequent work of others illustrates a more complex and nuanced picture which situates the individual in relation to others and in relation to the immediate physical and broader societal structures to which they belong. As a result, his work diminishes the experience of personhood by overlooking individual agency and citizenship rights.

This notwithstanding, Kitwood was one of a few theorists who were instrumental in bringing about a fundamental shift away from the medical model of dementia. He argued that *plwd* merit consideration as people with personhood, who should have their wellbeing needs understood and addressed. Others have subsequently used his work as the basis for further conceptual elaboration and empirical validation, so his work must be recognised for this. Other prominent researchers in the field of dementia such as Woods (2019, p.137) acknowledge that Kitwood's writing had sought to 'explain and convince', rather than setting out to provide a research-based appraisal of what wellbeing and personhood represent for *plwd*. However, Kitwood's work was grounded in real life; his observations were completed over a period of time working in care homes and day centres, He was one of the most influential writers in the field of dementia care (Baldwin & Capstick, 2007), his theories underpin the statutory guidance (NICE, 2018), DCM has been used globally. His theories of personhood, and the five needs (Kitwood, 1997) were considered most appropriate for this thesis as they support the intended outcomes of the intervention; enhanced wellbeing of *plwd*.

3.5.4.2 The theories of Allport and Pettigrew: Their general meaning and relevance for the intervention design

The following section discusses the four conditions of contact theory (Allport, 1954) and the additional condition of the opportunity to become friends added later by Pettigrew (1998). Although I did not aim to evaluate the theory as part of this research, it requires some critical appraisal as it did inform the design of the intervention. Each of the four concepts will be considered in the following sections, both in terms of their general meaning, and their relevance for the intervention design.

<u>General meaning of the concepts of contact theory</u>

1: Groups should have equal status during contact

Albeit covertly, Allport indicates that his understanding of equality means equality of *social status* and that achieving this should be the aim of an effective contact programme:

> 'To be maximally effective, contact and acquaintance programs should lead to a sense of equality in social status, should occur in ordinary purposeful pursuits, avoid artificiality, and if possible, enjoy the sanction of the community in which they occur. The deeper and more genuine the association, the greater it's effect' (1954, p.489).

From this description then, in broad terms equal status becomes synonymous with social equality and implies that people should be accepted as social equals, with no sense of superiority within or across individual relationships and that this can be achieved by people coming into contact through shared activity, the contact situation. Pettigrew (1998) later suggested that implicit in Allport's ideas was the idea that equal power would characterise the contact situation.

There is philosophical debate around the notion of social equality, but some of its main tenets are that it is a state that societies should aspire to as an ideal in terms of how individuals relate to each other, with the consequence that status divisions between people are not recognised, for example one race would not be deemed more or less superior than another (Fourie, 2011; Miller, 1997). Where social equality exists therefore, “people (will) stand in equal relations to each other rather than being treated as better or worse, inferior or superior’ (Fourie, 2011, p. 110). The foundation of social interactions will be that each individual has an equal standing and hence treat others as their equals (Miller, 1998).

Building on Allport’s initial work, Pettigrew and Tropp (2011, p.62) suggested that achieving equal status could be done by engineering contact situations which offered members of different groups equal opportunities to take part in activities; hence they would be enabled to express opinions and make decisions, thus giving everyone the means to exercise and shape rules of interaction.

Subsequent theorists have related Allport’s concept of equal status to intergenerational interventions, and more specifically those involving *plwd*. Teater for example (2016, p.4), who interviewed 12 young people after they had engaged in intergenerational activities with adults over 65, considered equal status to have been demonstrated as both groups could participate in, and shape the direction of the activity, without one group taking control of any aspect.

2. *The groups should work towards shared goals*

The second of Allport’s conditions was the pursuit of shared or common goals, arguing that any contact situation should involve this if positive interactions and a reduction in prejudicial behaviour were to be achieved (1954, p.281). Pettigrew (1998) and Pettrigrew and Tropp (2011) also echoed the importance of group members’ shared commitment to goal orientated efforts if contact was to be effective in reducing prejudice.

3. *Contact should be facilitated in a supportive environment sanctioned by the community*

Allport (1954, p.281) originally stated that: ‘the effect is greatly enhanced if this contact is sanctioned by institutional supports’’ (i.e., by law, custom or local atmosphere). Pettigrew, (1998, p.67) expanded on this by stating that: ‘With explicit sanction, intergroup contact is more readily accepted and has more positive effects’ and that’ authority support establishes norms of acceptance’. These statements do not explicitly state what conditions are required for an environment to be considered supportive but they infer a need for formal structure and authoritative permission or approval for the contact situation to be effective.

4. a) *Contact between the groups should be regular enough and long enough to develop true acquaintance*

b) *'The contact situation must provide the participants with the opportunity to become friends'* (Pettigrew 1998, p.59)

Allport's final condition of contact theory and Pettigrew's later tenet both recognised the importance of developing relationships as one of the ways to reduce prejudice or stereotyping and bring about positive interaction through contact with others. Implicit in both is the idea that for contact to be effective in bringing about attitudinal change, it must be regular or sustained enough to foster a relationship, even to the extent that it will be recognised as a bond of friendship. Neither Allport nor Pettigrew however stipulated the length of contact time required for such a relationship to develop, nor how the status of "friend" would be recognised.

3.5.4.3 Why the tenets of contact theory were the right focus for this thesis

Although contact theory has been deployed widely since the initial work published by Allport (see Chapter 3, section 5.3 for review of studies drawing on his work), the four conditions which underpin it have been the subject of criticism, in particular because they say nothing about the context in which the contact needs to take place (Pettigrew, 2021, p.262). The following section addresses the question as to why the theory was nonetheless relevant to adopt in my research, by shedding a critical lens on Allport and Pettrigrew's work on the role of contact in reducing prejudice, by considering its use and relevance when observing intergenerational contact in a care home setting. My analysis is informed here in part by the literature drawn on for the design and fieldwork elements of my research (Chapter 9, section 2).

Equal status

Focusing on equal status in the care home environment as a context of contact was considered important because it encapsulated the research objectives of providing a positive intervention experience for both groups of participants, enhancing the wellbeing of residents, and shaping the perception of *plwd* amongst students.

There is evidence to indicate that care home residents living with dementia hold low status and that a reduction in self-perceived social status accompanies a diagnosis of dementia. Research by Clare (2008), Langdon et al (2007) and Patterson et al (2018) has shown that *plwd* perceive themselves as having low status. Langdon et al's work (2007) highlighted an 'Awareness of loss of social status and familiar work and social roles' as a key them emerging from interviews with 12 people living with dementia, recruited through a mental health unit in London, and were asked how they felt others perceived them. Similar findings have been reported in wider samples. In a literature review of 23 qualitative studies completed in the UK, USA, Canada, Sweden, Norway, New Zealand and China which explored how people living with dementia perceive 'the attitudes, views and perception' of others towards them 'being treated as lesser rather than a full, valued member of society' was found to be one of four major themes (Patterson et al, 2018, p.791). The social status of people living with dementia in care homes may be the lowest of all. In a study completed in care homes in the UK, Clare et al, (2008, p.711) spoke to 80 care home residents living with dementia and found 'a sense of worthlessness' a feature of the experience.

More contemporary research has indicated that the population in general perceive *plwd* in care homes as low status. Research completed in Australia which focused on segregation and confinement in care homes and was based on interviews and focus groups with residents living with dementia, care partners, aged care workers, lawyers and advocates, found that residents living with dementia experienced stigma (Steele et al, 2020). The authors conclude that 'the community at large either had an interest in keeping them locked up out of sight or were simply not aware or did not care about their circumstances' (p.317).

In sum, this body of evidence suggests that the two groups involved in this research, students and residents living with dementia, would arguably have been disparate in terms of perceived social status when coming into contact in the care home context. There is a likelihood that residents living with dementia would have been the 'lower status group'.

The research design represented an objective aspiration to facilitate a situation where equal status could develop unhampered through contact between *plwd* and students. My approach to facilitating this through the intervention is outlined in detail elsewhere (see Table 8, p. 79 of thesis). Given that neither group was teaching the other, nor showing them what to do, there is arguably no inherent power dynamic in their contact – one group is not superior to another in terms of their abilities to master the intervention, rather it is based on interaction. In this sense both groups had the power to shape these interactions. There is support for this in the findings which are discussed in Chapter 9 section 2, pp 217-218.

Common Goals

Focusing on common goals was considered important for the research as a way of making the intervention activities meaningful for participants and for stimulating group interactions. There is also evidence from the literature to suggest that focusing on common goals is important in IG interventions aimed at challenging stereotypes of older adults. Teater (2016, p.110) found that the common goal of art acted as a distractor, a mediator, and a bonding agent. Young participants (aged 11-12) who had worked with older adults to draw and paint a portrait, found that art provided a distractor at the beginning of the intervention, when they were nervous, and had 'ran out of things to say'. However, very quickly the art became a channel for contact by bringing the participants together, and enabling them to feel relaxed in each other's' company and supportive. Lokon et al (2017) also found that having a common task of creating artwork provided an important contributing element to relationship-building.

A supportive environment sanctioned by the community

The intervention which formed the basis of this thesis was delivered in what can be considered a supportive environment; this was an important factor taken into account in the selection of the study setting so that *plwd* could feel safe and secure. The selection of care home sites was based on my assessment of their suitability for the type of research project proposed (see Chapter 5, section 2.2), and followed by close liaison with care home managers and staff about intervention activities, participant recruitment and support during the activity sessions. Furthermore, the study was authorised, supported and considered valuable for *plwd* by area and care home management teams and staff from the outset, with all parties expressing an interest in hosting the intervention.

Regular and sustained contact between the groups for relationship and friendship formation

Cooperation and relationships were important factors on which to base the intervention, notably because of their potential to improve the wellbeing of residents, as the opportunity to build friendships with people from outside of care homes is limited. It is also true to say that simply being in the same care home as someone else is not necessarily the recipe for friendship. This is supported by other research examining friendship amongst *plwd* living in care homes which found that social opportunities in the residential care setting did not meet the *plwd's* expectations of friendship (Casey et al, 2016, p.865).

Satisfying Allport and Pettigrew's tenets on this may be more challenging in contact situations with *plwd*, as research indicates that their friendship experiences may be unique. DeMederios and Sabat (2013, p.216) suggest that: 'People living with dementia live outside the boundaries of traditional friendship because changes in memory, residence, and social opportunities create fundamentally different friendship experiences and opportunities for them than what is generally described in the literature' (p.216). Kutner et al (2000, p.90) define friendship in the context of dementia as: 'continued interaction of specified individuals over an extended time period'.

The study was designed with building relationships in mind. The intervention provided opportunities for *plwd* to meet young people, and to become involved in activities based on mealtimes which are recognised as conducive to building friendships (Jarrott and Smith, 2010). DeMederios et al (2011) research on friendships amongst people living with dementia in residential care found that staff had reported that close physical proximity between residents, particularly during mealtimes, was an important mechanism in determining who they were likely to interact with and establish friendships with.

To conclude, Whilst Allport and Pettigrew's work says nothing about the context in which the contact takes place I have outlined here the rationale for basing the intervention on these theories. In Chapter 9 Section 2 I discuss my findings in relation to assessing whether the tenets of contact theory were the correct factors to focus on.

3.5.5 Incorporating theory to the intervention design

Kitwood's philosophy of care (1997), and contact theory, developed by Allport (1954), and later Pettigrew (1998) provided a framework on which to design the components of the intervention. What the theories have in common is an emphasis on relationship; Kitwood (1997) suggests that relationship is at the centre of person-centred care, and Pettigrew (1998) suggests that friendship is the mediator that underpins attitude change during contact. Both theories suggest that it is relationship that effects change.

The intervention sought to enhance personhood by meeting the five basic needs of *plwd* identified by Kitwood (1997), and bring about a change in student attitudes by satisfying the tenets of Contact Theory (Allport, 1954, Pettigrew, 1998), which are discussed in Chapter 2.

There are a number of broad points of convergence in these theories; relationship, collaboration, comfort, and equality feature in both. Table 8 illustrates how intervention components are underpinned by both theories. For example, both groups of participants were treated equally during the intervention, the use of the PAL profile, and oral and verbal instructions for *plwd* were aimed to include them on an equal basis, as much as possible.

Table 8: *I*ntervention components that are underpinned by theory

Kitwood’s philosophy of needs (1997)	Intervention Components That Satisfy Elements of Theory	Contact Theory Allport (1954), *Pettigrew (1998)*
Attachment	Providing a context in which *relationships can thrive* Introducing student volunteers to a care home context as a means of fostering relationships. The intervention was designed to last approximately 40 mins to an hour once a week for four weeks. The intervention was designed to facilitate 1:1 contact, which provided participants with the opportunity to become friends.	**Contact between the groups should be regular enough and long enough to develop true acquaintance** **The contact situation must provide the participants with the opportunity to become friends**
Occupation ***Collaboration***	Preparing and sharing food was the basis of the intervention, which was considered meaningful occupation. *Plwd*/student dyads worked together to prepare the food, which they ate.	**The groups should work towards shared goals**
Comfort	The planned intervention was delivered in the comfort of participants homes with other residents and staff on hand to offer support. The research team collaborated with the care home manager and staff. Members of care staff were present during the activities.	**Contact between the groups should be in a supportive, normative environment.**
Inclusion	The activities were designed to match the abilities of the *plwd* included in the study. An OT, and the PAL occupational Profile (Pool, 2010) tool were used to do this. They are discussed fully in Chapter 6, section 4. Verbal instructions were delivered by the facilitator and printed instructions were made by the research team. See Appendix 3 *Plwd* and students were all participants in the study and were treated equally	**Groups should have equal status during contact.**
Identity	*Plwd* were provided with the opportunity to reminisce, and to express their identity through choice, about whether to complete activities or not, and what fruit to put into the fruit salad, for example.	

3.6 OUTPUTS FROM THE LITERATURE REVIEW

The review of the literature presented here informed the design of the intervention and facilitated a revision of the study aims and research questions. These two areas will now be discussed.

The design of the intervention was informed by evidence from the literature review. In sum, the intervention was planned to be delivered once a week for four weeks; each activity session was expected to last approximately an hour. The participants would complete activities in pairs, one *plwd* would be paired with a resident in the RO intervention, or a student in the IG intervention. An activities facilitator would be appointed to deliver the activities, staff would be present to safeguard and support participants, and I, as the researcher would have minimum input during the activity sessions. Students would be provided with an information event at the university, and an induction at the care home. The individual activities chosen are discussed in Chapter 5, section 2.

At the outset, this study was funded with the purpose of designing, piloting and evaluating an IG intervention, which linked university students under 25 with people living with mild to moderate dementia (*plwd*) who reside within a care home. The aim of the intervention was to enhance the wellbeing of *plwd* by offering meaningful activity through food preparation and sharing, and engagement with the outside world, whilst improving the knowledge and attitudes of the students towards people living with dementia.

The literature reviewed in the previous chapters has not only validated the need for such an intervention – with its specific focus on *plwd* and university students, and the use of food preparation and sharing as a vehicle to facilitate wellbeing and understanding for all parties in the care home context. It has also pointed to the importance of exploring the implementation of the intervention from a third perspective, that of the care home staff. The literature reviewed illustrated the key role that staff play in IG interventions in care homes; it is important that their experience of the intervention is positive. Therefore, the views of care home staff were sought in relation to the experience of the *plwd* who completed the intervention; any challenges that care home staff faced implementing the intervention, and the likelihood of the care home introducing this intervention or something similar in the future.

The literature review has also enabled a more precise, evidenced-based formulation of specific research questions this thesis will address. These are:

1. Does the proposed intervention have the potential to enhance the wellbeing of *plwd* as outlined by Kitwood (1997)
2. Does it have the potential to improve the knowledge of, and comfort with *plwd* amongst university students?
3. What challenges may care homes face in implementing the intervention?

4 CHAPTER 4: THE METHODOLOGY

The aim of this chapter is to present the research design in detail, including the research paradigm, the methodological approach and data collection methods used, followed by discussion of the considerations and process of ethics. It begins by introducing the research design including the underpinning epistemological stance and ontological position before providing a rationale for the evaluation of the intervention. This thesis adopted a pragmatic approach and focused upon developing and implementing a complex intervention. The pragmatic approach enabled the use of MM for data collection and provided the researcher with the opportunity to explore the implementation and outcomes of the intervention from a number of perspectives; care home staff, residents, and students.

4.1 PRAGMATISM AS A RESEARCH PARADIGM

This thesis has been influenced by a pragmatist worldview or paradigm. Whilst there is general agreement that a paradigm is a set of beliefs held by the researcher that underpins the methodology and methods of their research, there is no clear consensus about the precise nature of this set of beliefs (Morgan, 2007). Kuhn (2012) was the first to relate paradigms to science (Kuhn, 2012, p.43), describing a paradigm as a body of knowledge upheld by a scientific group that included accepted theory, successful applications of this theory, and comparisons with other theories. Kuhn (1962) identified two characteristics that this knowledge must hold to satisfy his definition of a paradigm; that it was ‘sufficiently unprecedented’ to ‘attract people away from competing models’ yet ‘open’ enough to allow for further development.

Debate about the nature of paradigms ensued. Masterman (1970) for example, argued that Kuhn (2012) had defined the term ‘paradigm’ in at least 21 different ways in his original writing. Patton (1978, p.203) described a paradigm as ‘a world view, a general perspective, a way of breaking down the complexity of the real world’. Guba (1990, p.7) described a paradigm as a ‘basic set of beliefs that guide action’ which is characterised by the researchers’ answers to 3 questions. The first question relates to ontology: what is the nature of ‘the knowable’ or reality? The second question relates to epistemology: what is the relationship between the knower (inquirer) and the known (or knowable)? The third relates to methodology: how should the inquirer go about finding out knowledge? (Guba, 1990, p.18). According to Guba the paradigm underpins the ontology and the epistemology which in turn drive the methodology (paradigm › ontology › epistemology › methodology). However, Crotty (1998) equates 'paradigm' to epistemology and suggests that the epistemological stance of a researcher underpins the research process (epistemology › theoretical perspective › methodology › methods). Creswell (1998) suggests that axiology (values/ethics) should also be considered within a paradigm. Whilst it can be seen that conceptualisations of a paradigm differ, there is general agreement that the methodology and the methods of research are driven by a theoretical set of beliefs.

Guber and Lincoln (1994, p.114) stressed the importance of paradigms in the research process stating that: 'no inquirer, we maintain, ought to go about the business of inquiry without being clear about just what paradigm informs and guides his or her approach'. Crotty (1998, p. 2) agrees that the rationale behind a researcher's choice of methodology and method: 'reaches into the assumptions about reality that we bring to our work'. Creswell (2015a, p.2) states that the 'procedures for conducting research evolve from a researcher's philosophical and theoretical stance'.

In line with the research aims, pragmatism was identified as a suitable paradigm as it is concerned with problems and how to solve them. The focus of pragmatic inquiry is on situations, actions, and consequences (Creswell, 2015); in this thesis the care home environment represents the situation, the intervention the action and the related outcomes the consequences.

Pragmatism was developed as a philosophy in the USA at the end of the 19th century with the work of key theorists including Charles Sanders Pierce, William James and John Dewey (Feilzer, 2009; Morgan, 2017), but emerged in the literature as a paradigm for research at the beginning of the 21st century (Howe, 1998; Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 1998). Pragmatism rejects the dichotomous view of the positivist versus constructionist schools of thought, instead referring to an 'experiential world with different elements or layers, some objective, some subjective, and some a mixture of the two' (Feilzer, 2009, p.8).

Pragmatism also rejects the view that there is an absolute truth. Dewey (1958, p.158) related knowledge to action, and wrote of 'using things as means to affect other things', asserting that the organism and the environment ‘in transaction’ create knowledge. In this way knowledge is always a human construction but must be based on ‘something that is already there’. Denscombe (2014, p. 158) argues that newly found knowledge must be used to modify previous knowledge therefore ‘is provisional’ and contextual, based on the time and place. As Biesta (2015, p.2) states ‘knowledge can provide us only with information about possible connections between actions and consequences, not with once-and-for-all truths. Accepting this premise, knowledge generated from the current thesis will be ‘contextual’, that is a product of the time and the place, in this instance, residents with dementia and young people in a number of care homes in South Wales in 2017.

4.2 MIXED METHODS

A MM approach can be defined as; ‘the combination of qualitative and quantitative approaches in the methodology of a study’ (Tashakkori & Teddlie, 1998, p.ix) which has been applied to this study. There is some debate about the terminology of MM. Tashakorrie and Teddlie (2003) discuss: i) multimethod: two or more methods from same philosophical stance qualitative or quantitative (Campbell & Fiske, 1959, for example), ii) MM using qualitative and quantitative data collection and analysis techniques, and iii) mixed models as described above. Bryman (2016, cited in Cresswell & Cresswell, 2018, p.215) suggests that MM covers all of the above, which is now generally accepted.

Pragmatism supports the use of MM, the approach adopted for this study: pragmatism does not expect to find unvarying causal links or truths but aims to interrogate a particular question, theory, or phenomenon with the most appropriate research methods (Feilzer, 2009, p.13). There was intense debate during the 1980s about mixing paradigms. Denzin (1970) proposed the use of triangulation, combining the use of a number of methods to improve the results in social science research. Lincoln and Guba (1985) proposed natural inquiry as a paradigm, which later became known as constructivism, and support for a constructivist paradigm grew. The ‘incompatibility thesis’ which suggested that methods could not be mixed, was argued based on the link between epistemology, ontology and method (Guba, 1990). Howe (1998) argued against the incompatibility thesis and for pragmatism as a paradigm.

Melville (2013) suggests that qualitative methods are the most appropriate for IP research however Pain (2005) disagrees; he advocates a MM approach as being the most appropriate for IP studies due to the likely outcomes (Pain, 2005). George (2011, p.935) states that researchers use MM for IG volunteering, which is; ‘a complex relational phenomenon’. He suggests that a mix of methods provides a deeper insight into the QOL of *plwd* than any individual research method could, and warns researchers not to rely on ‘psychometric or narrative data’ and to include observation.

4.3 ADOPTING AN EXPERIMENTAL FRAMEWORK FOR MIXED METHODS QUANTITATIVE AND QUALITATIVE DATA

A MM methods approach was adopted for this research because it enabled the researcher to answer the research questions from a number of perspectives, assess changes resulting from the intervention alongside the complex processes underlying change, and corroborate researcher observations with data gathered from participants, and care home staff.

There are three key MM designs; convergent, explanatory-sequential, or exploratory-sequential. Convergent designs, where qualitative and quantitative data is gathered at the same time and compared and contrasted, are typically used when gathering two types of data from the same participant group, for example in this case residents living with dementia). Explanatory sequential (quantitative data informs subsequent qualitative data) or exploratory sequential (qualitative data informs subsequent quantitative data) (Creswell & Creswell, 2018). None of these designs were suitable for the complexity of this project as it sought to answer a number of research questions from the perspectives of three participant groups: residents, students and carers.

This intervention has many elements therefore a complex application was required. According to Creswell and Plano Clark (2018) complex applications are suitable for small scale exploratory projects such as this one. Cresswell and Plano Clark (2018) identify 4 complex MM designs; experimental or intervention, case study, participatory-social justice framework, program evaluation design, but recognise that they are not exhaustive. urging researchers to select a core design that matches the research aims and questions. As none of these designs were a perfect match for the current study, I selected an experimental design as a core, and designed a methodology, loosely on this, which I now outline.

The framework adopted for this thesis most closely represented an MM experimental framework. A quasi-experimental pre-test post-test design with a non-equivalent control group was used to assess change in the mood and engagement, and behaviour of *plwd* across three time points, before, during and after the activities. Qualitative data served as a broader explanatory framework for these findings. Qualitative data was also gathered to explore any challenges that care home staff experienced in implementing the intervention. Additionally, in the IG intervention, a within group pre-test post-test design was used to assess change in students' attitudes towards dementia.

A quasi-experimental design was chosen to evaluate changes in: ME of *plwd* and students' attitudes towards dementia, as the conditions of a true experimental design could not be met. True experiments involve two groups of participants and researcher manipulation of an independent variable (IV) to assess the impact on a dependent variable (DV). Data is collected in a controlled environment (lab or field), variables are measured pre-test and post-test, and cause and effect can be claimed. Participants are randomly assigned to the treatment or control group groups, which are matched on variables such as age, and gender, for example (Denscombe, 2014).

The strict controls of true experiments have strengths and limitations, they offer high internal validity as strong claims can be made about the relationship between independent and dependent variables. However, the lab-based environment in which they are typically based poses a challenge to their external validity; the question remains as to whether results represent the reality of life. The current intervention was completed in a care home setting, which addresses the issue of external validity, as it is a 'real life' setting. However, the care home environment meant that a quasi-experimental framework was the most appropriate as the strict controls of true experiments could not be satisfied; groups of *plwd* could not be randomly assigned, as they were pre-existing.

There are a number of quasi-experimental research designs (Aussems et al., 2009) including one group designs, and non-equivalent group designs; both were used within this thesis. A non-equivalent pre-test, post-test group design was used to assess changes in the ME of *plwd*, to compare the experience of the IG group with the RO group. The RO group acted as the control. A one group pre-test, post-test design was used to assess changes in the attitudes of students towards dementia.

All quasi-experimental designs include challenges to internal validity; however, a number of strategies were used to address this in this thesis. A non-equivalent group pre-test post-test design was implemented to assess changes in ME of the *plwd* as the control group (RO) and the treatment group (IG) were pre-existing, not randomly assigned and matched. This selection bias poses a threat to internal validity as any differences found between the groups may be as a result of group differences rather than effects of the intervention. A number of strategies can be adopted to address this including pre-test post-test measures and larger sample sizes, for example (Aussems et al., 2009). Pre-test post-test measures were included in the research design, however increasing the sample size was not practical.

A one group quasi-experimental design was used to measure changes in the knowledge and attitudes of students; however, this has limitations as there is no control group for comparison. To minimise this threat a pre-test post-test design was implemented. However, this does not eliminate the threat, which will be considered when drawing conclusions from this data.

The experimental controls used are a strength and limitation when evaluating interventions; they offer scientific rigour but are unable to account for real life effects (Tarquinio et al., 2015), therefore qualitative data was also embedded into the overall experimental framework using focus groups. There are several reasons why qualitative data are needed in this study. First, it provides a larger ‘real-life’ picture of the nuances of the study, from a number of perspectives, as opposed to the linear cause and effect of the experimental framework. Second it offered participants an opportunity to provide feedback that was unconstrained; the data collection tools were designed to give participants the opportunity to respond to open ended questions (see Appendices 8 & 9). This approach to data collection therefore enabled their meaning and interpretation of the experience to be explored, alongside the meaning ascribed to the situation by the researcher (Creswell & Creswell, 2018). Finally, and as suggested by Feilzer (2009), without the qualitative element the research would have been ‘little more than a snapshot, a photograph of a social experiment without the subtitle enabling it to come to life' (p.13).

4.3.1 Data triangulation

The theory of triangulation is based in trigonometry and was proposed for use in the social sciences by Denzin (1970). Triangulation can be used in a number of ways, for example to seek convergence which increases the validity of results (Cresswell & Creswell, 2018); if the findings from the data are divergent then the researchers need to seek reasons for that (Plano Clark & Ivankova, 2016). Triangulation can also be used to develop a more complete picture (complementary) which is the case in this study; DCM numerical data was gathered to explore changes in mood and engagement, qualitative data was gathered to explain underpinning factors associated with the change (Plano Clark & Ivankova, 2016).

Patton (2015) describes 4 types of triangulations:

1. Qualitative sources: data from different sources
2. Qual/Quant methods: data from different
3. Analyst: different researchers, for example
4. Different theories…Comparing perspectives of different points of view

Based on Patton's definition, triangulation of Qualitative/Quantitative methods, and analyst triangulation were used in this study. Between methods triangulation allowed comparisons to be drawn between a number of data types. To explore the experience of *plwd* the DCM data was triangulated with data from participant activity feedback sheets, and qualitative data gathered during focus groups. For example, I explored how my scoring on DCM compared to the level of wellbeing that participants expressed after the activities on the activity feedback sheet. I also triangulated the scores and DCM notes with the descriptions provided by *plwd* of their experience, and the observations that care staff described. This provided a greater validity to the findings than using data gathered from a single data collection method, or from one perspective. Results using this approach are discussed in Chapter 6. Secondly, after each activity session I discussed my reflexive observations with the activity facilitator during a 'debrief' session., in which we discussed and compared our observations.

The data collection methods and tools used during this thesis are presented in detail in the following section.

4.4 DATA COLLECTION METHODS

4.5.1 Dementia Care Mapping (DCM)

The main research method used to evaluate the effect of the intervention on the mood and engagement (ME) of *plwd* was researcher observation using DCM (Brooker & Surr, 2006). There are a number of rationales for using DCM in the current thesis. Firstly, the method aims to represent the experience of *plwd* from their perspective whilst it may be challenging for the individual to self-report on their experience. Secondly, it is an established method which is widely used within the care sector throughout the UK and internationally (University of Bradford, 2016b). Within Wales a shortened version (SOFI), is used by CIW as part of their assessments on the quality of care provided in care homes (CIW, 2018). Additionally, it provides an abundance of data which enabled the researcher to track the ME of *plwd* over time, therefore enabling the researcher to explore the experience of *plwd* during the intervention, and to assess changes in ME that resulted from it. There are at least 11 observational methods which assess the QOL of *plwd* however DCM is the most detailed (Algar et al., 2014).

DCM can be considered a MM tool as data gathered and analysed is both qualitative and quantitative. ME scores ranging from -5 to +5 are recorded alongside qualitative data; behaviour category codes (BCC) which indicate the behaviour that the *plwd* is engaged in and explanatory notes. A mapper using DCM observes *plwd* and records their observations at regular five-minute intervals. For each 5-minute timeframe the mapper records the main activity (BCC) that the individual was engaged in, their level of mood and engagement (ME value), and interactions with carers that have supported or challenged their well-being (Personal Enhancers [PE] and Personal detractors [PD]).

Observational research methods have strengths and limitations. Whilst they enable researchers to observe behaviour as it happens and collect data ‘that would require dozens of interviews or focus groups to uncover’ (Guest et al., 2013, p.82) they are time consuming, and may not compare to the participant experience. A number of researchers have investigated whether DCM data correlates with self-report data of *plwd* with mixed results. Fossey et al. (2002, p.1068) found a significant correlation between DCM WIB scores and self-report QOL scales completed by *plwd* in care home settings. Edelman et al. (2005) found a moderate correlation between DCM data and *plwd* self-report data gathered in assisted living facilities but no correlation between the data gathered in special care facilities. It is therefore difficult to draw firm conclusions regarding this issue plus the studies cited were completed using DCM 7 therefore may not be applicable to DCM 8. The mere act of observing may change the behaviour of the participants observed (McCambridge et al., 2014). To address this issue the researcher visited the care homes for a number of weeks before the intervention began to build rapport with the participants in order that they would feel comfortable to engage in their usual behaviour when being observed by the researcher.

A number of methodological limitations of DCM have been reported in the literature. These limitations and how they may affect this thesis will now be discussed. DCM is time and resource intensive (Algar et al., 2014; Cooke & Chaudhury 2012; Fulton et al., 2006). Four hours or 48 timeframes of data is required to assess average wellbeing/illbeing (WIB) scores (University of Bradford, 2016a) however no rationale is provided for this (Cooke & Chaudhury, 2012). Despite this, a number of intervention studies have calculated ME values with fewer timeframes. Hsu et al. (2015) calculated average ME over a period of 24 TF's, Crook et al. (2016) used 18TF's, Kontos et al. (2016) used 15TF's. This affected the analyses that I could complete using pre-test post-test data, which is discussed fully in Chapter 6.

The calculations used to determine the BCC and WIB scores for each 5-minute timeframe are complex (Cooke & Chaudhury, 2012), and theoretically, as opposed to empirically, derived (Sloane et al., 2007). The 5-minute TF's and calculations under represent the time that *plwd* spend 'socially passive, withdrawn or disengaged' (Thornton et al., 2004, p.725) as preference is given to BCC with the highest potential for wellbeing (Cooke & Chaudhury, 2012). Whilst these claims have some merit their effect on this study is minimal as the results were based on comparisons (between groups) and the same protocol was used for all data. Therefore, the comparisons were made between data which all had the same limitations.

The question has been raised as to whether there are too many BCC's which puts the validity of the codes into question. The suggestion has been made that the number of codes could be collapsed for research purposes (Cooke & Chaudhury, 2012). Only 10 of the possible 23 BCC's were observed in the current thesis therefore a collapsed version may have been applicable however the nature of the BCC's would depend on the components of an intervention. As this intervention was based on preparing and sharing food the percentage of F codes were not unexpectedly high, for example.

There is some debate as to whether DCM is sensitive to change. Brooker (2005) claimed that it is, however Cooke and Choudry (2012) state 'intervention studies rest on the assumption that DCM is sensitive to change which has not been tested properly' (p.801). Despite the limitations cited (Fossey et al., 2002, p.1064) concluded that 'DCM is a valid tool for the longitudinal evaluation of quality of life in people with dementia in care settings. Sloane et al. (2007, p.580) said that 'DCM has promise as a research measure, as it may come closer to rating QOL from the perspective of persons with dementia than other available measures, however the utility of it will depend on the manner in which it is applied and an appreciation of the measure's strengths and limitations. The researcher has an appreciation of the limitations of DCM and how this may affect the results of the current study.

A number of studies have used DCM 8 to evaluate the effect of short psychosocial therapeutic interventions on the QoL of *plwd*. The length of interventions assessed using DCM 8 have lasted between 30 minutes and 2 hours each session on a weekly basis, and have been delivered over a period of time ranging from two days to five months. Six interventions were delivered in care homes and included activities such as: music therapy (Hsu et al., 2015), the use of life story book and rummage boxes (Crook et al., 2016), elder clowning (Kontos, et al., 2016), iPad applications (Leng et al., 2014), group reminiscence arts sessions (Keating et al., 2018), and music therapy and spiritual care (Kirkland et al., 2014). One intervention was delivered in a community support programme attached to a long-term care home (Hall et al., 2018), and two in day care centres (Leng et al., 2014; Koh et al., 2019). The factors that were explored in these studies included average ME values or WIB scores, the amount of time that participants spent in each of the ME values, and the amount of time that participants spent engaged in each BCC. Few studies measured Personal Enhancers

(PE’s) and Personal Distractors (PD’s); positive interactions between care staff and residents which uphold personhood (PE), and negative interactions (PD’s) which do not. Hsu et al. (2015) included PDs and PDs as part of the study, Leng et al. (2018) recorded them but did not report them, and Kirkland et al. (2014), recorded PEs and PDs relating to interactions between the intervention facilitators and the *plwd*, to evaluate the skills and practice of the activity leaders.

A number of research designs were used to evaluate the interventions; three studies mapped the activity sessions only; Kirkland et al. (2014) and Leng et al. (2018) focused on descriptive analysis of the experience of participants during the spirituality and music therapy, and horticultural sessions while Yeo et al. (2014) compared the experiences of participants during 4 different activities (craft, cooking, and two iPad sessions). One study completed a base-line mapping session before the intervention started which was followed by mapping of the activities (life story books, rummage boxes and a control condition); analyses were completed which compared results from all of the mapping sessions. Four studies used a pre-test post-test design in which DCM was completed before, during and after the intervention, however the pre-test post-test measures were taken at a variety of points.

Pre-test and post-test measures were taken before the intervention started and at a number of time points throughout the intervention in two studies. Hsu et al. (2015) mapped participants for 2 hours over lunch time at baseline, 3 months, 5 months and 7 months (post intervention), Kontos et al. (2016) mapped participants for 6 hours before their 12-week elder clowning intervention started, and again at 4 weeks, 8 weeks and 12 weeks. Neither of these studies completed mapping during the activity sessions. In the third study Koh et al. (2019) mapped participants pre-post each activity session but not pre-post the whole intervention; each participant was mapped for 30 minutes immediately before and after the weekly dance session plus the hour of the dance session. Keating et al. (2018) combined both approaches; they completed l hour-long mapping before the intervention started and 3 months after it was finished. They also completed weekly mapping sessions of 30 minutes immediately before and after group reminiscence plus the hour of the group reminiscence.

All four of these studies analysed average group WIB scores across time using a variety of statistical tests; Hsu et al. (2015) used ANOVA to measure difference within and between subjects using an intervention and control group, Keating et al. (2018) used statistical modelling using Stata. Koh et al. (2019) used paired t-tests or Wilcoxon, between groups when comparing data from two groups, Krusaki Wallace when comparing data from three groups. Kontos et al. (2016) did not have a control group therefore used t-tests to assess changes over time.

All of the studies reported statistically significant improvements in the average ME of *plwd* as a result of the intervention, however, all of these studies involved larger sample sizes than this study. The study completed by *Hsu et al.* (2015) involved the least participants (17) the study completed by Keating et al. (2018) included 75 participants. There are limitations to using each of the pre-test post-test time points. It is difficult to state with conviction that any increases in measures taken before, during and after an 8-week intervention result from the intervention as there may have been many other events which happened during that period that resulted in the increase. For example, Kontos et al. (2016) reported a significant improvement in the wellbeing of participants during the 12-week period of their study which they credited to the elder clowning. However, the intervention lasted 20 minutes per week, a small proportion of the week in which many other things may have occurred to account for the reported change. There are challenges in taking measures immediately before and after each activity session too. An activity involves some preparation time where researchers, activity facilitators, care home staff, and participants arrive and prepare for the session. Similarly, after the session some time is needed to pack up and move back into the typical life of a care home. It is challenging to identify exactly where an activity session starts and finishes and subsequently analyse differences between the participant experience of the activity session and the typical daily life of a care home. These studies informed the design of the current study which adopted a combination of these approaches for; pre-test post-test measures were collected on *plwd* using DCM data each week and before and after the 4-week intervention, questionnaire data was gathered from students pre and post intervention.

To conclude DCM is an observational tool that originated in the 1990s to evaluate the efficacy of care from the perspective of *plwd*. It has been developed by practitioners since and is now in the 8th edition which has been used to evaluate interventions; eight of which have been reviewed here. These studies generally explored the average ME values experienced by *plwd*, and/or the length of time that *plwd* spent in each BCC and ME value. Four of the intervention evaluation designs were pre-test post-test, two assessed measures before and after the intervention, one assessed measure before, during, and after each weekly session, the fourth integrated both designs. Activity session feedback sheets.

4.4.1 Feedback sheets

Feedback sheets were used to provide participants with a quick, simple, and anonymous method to express their mood after each activity session. The sheets were designed with 5 options ranging from very sad to very happy represented in pictures and words (see Appendix 6). Feedback or ‘happy sheets’ sheets have traditionally been used within the field of education to evaluate training sessions and can be useful for gauging how much participants enjoyed the training (Lambert, 2012). They were used within this study to assess the immediate reactions of participants to the activities and their feelings at that moment. The researcher also believed that the sheets would be able to identify any problems that participants encountered with the activities immediately (Annabel Jackson Associates, 2002).

4.4.2 Student questionnaires

Self-completion paper-based questionnaires were used to evaluate changes in student knowledge and attitudes as the information that the researcher was seeking was straightforward (Denscombe, 2014), and questionnaires were considered convenient, and quick to administer and complete (Bryman, 2016). The questionnaire designed for this study (Appendix 7) asked participants for demographic information including age and gender and whether they knew anybody living with dementia. If the participant answered yes, they were asked what their relationship was with this person and how often they see them. This was followed by two tasks; DAS (O'Connor & McFadden, 2010), and a word-based task used in previous studies by Harris and Caporella (2014).

Two validated scales were identified which measure attitudes to dementia in young adults and were considered for use; DAS (O’Connor & McFadden, 2010), and a questionnaire developed by Lundquist and Ready (2008). Both items were developed with undergraduate students and have demonstrated good reliability and validity. The scale developed by Lundquist and Ready (2008) includes 10 items and two subscales;

personal sacrifice and sympathy. The DAS (O'Connor & McFadden, 2010) includes 20 items and two subscales; comfort and knowledge. This scale was adopted for this thesis as it is psychometrically robust, was originally validated for students and has been used in a number of IG studies (Garrie et al. 2016; George et al., 2013; Lokon et al., 2017).

The DAS (O'Connor & McFadden, 2010) is based upon the tripartite model of attitudes; a theory which suggests that attitudes have three components; affective, behavioural and cognitive. The scale was developed using input from people living with dementia and their carers’. Structured interviews were completed by five family caregivers, five dementia care professionals and five undergraduate students with limited knowledge of dementia, resulting in a scale with 46 items. The original scale was trialled on 307 undergraduate psychology, biology and special education students. Factor analysis of the completed scales resulted in exclusion of 16 items. The resultant 30 item scale was then completed by 105 nursing students and results underwent another Exploratory Factor Analysis which resulted in a 20-item scale with two factors (comfort and knowledge). This is the scale that was used in this study.

The scale is scored on a 7-point Likert scale with responses ranging from 1 (strongly agree) to 7 (strongly disagree); ten items assess the subscale of comfort and 10 assess the subscale of knowledge. Six of the twenty items (2, 6, 8, 9, 16 & 17) are reverse scored. Scores for the factors of comfort and knowledge range from 10-70 and scores for overall scale range from 20-140. The DAS was considered most appropriate for this thesis as it involved more items and the sub scales closely matched the aims of the study. However, the DAS provides predetermined options for participants which may reflect the perspective of the researcher to a greater extent than that of the participant (Denscombe, 2014). A second phenomenological task was therefore included in the questionnaire to afford the participants the opportunity to determine their own responses.

This phenomenological task has been used in previous research completed by Sabat (2011) and Harris and Caporella (2014). Harris and Caporella (2014) asked college students, in a study which assessed the effectiveness of an IG choir in changing student towards *plwd* to write down 10 words to describe images that ‘come to mind when you hear the word AD or dementia’. Students were asked to complete the task pre- and post- their involvement with the choir. Researchers subsequently scored the words generated as negative, neutral or positive and calculated changes in the number of replies in each category before and after the intervention. This approach offers students the opportunity to generate words or themes therefore it has the potential to uncover factors or themes that are not covered by the DAS (O'Connor & McFadden, 2010). Yamashita et al. (2011) suggested that IG service-learning programmes include pre-test post-test designs with multiple measures both quantitative and qualitative. All information was generated by students as opposed to them being asked to rate factors from a previously formatted list, some of which may not be relevant to them. However, the approach has some limitations; there is an issue of subjectivity as the researcher decides whether words are positive, negative or neutral. To overcome this in the present study the researcher asked 4 other researchers to rate each of the words in the list generated by the students as either positive, negative or neutral which provided a consensus.

4.4.3 Focus groups

Focus groups bring small groups of participants together, typically between six and nine participants but on occasion as few as two, to discuss their views, experiences and opinions of a given topic. Discussions tend to last approximately one and a half to two hours and stimulus materials can be included (Denscombe, 2014; Wilkinson, 2015). Discussions during focus groups can illustrate a consensus or difference between participants views and perceptions. They therefore provide the researcher with an opportunity to assess the extent of shared views (Denscombe, 2014; Wilkinson, 2015). Participants are encouraged to engage in discussions with each other which may involve interaction such as jokes, laughter, persuasion and disagreement therefore providing a more naturalistic setting than interviews (Wilkinson, 2015).

The practical benefits of focus groups are that they facilitate the collection of considerable data in a short time (Wilkinson, 2015). They have been found appropriate and enjoyable for people with moderate to severe dementia (Casey & Murphy, 2014; Bamford & Bruce, 2002). Focus groups involving *plwd* have tended to involve 3 to 5 participants, however have been completed with as few as 2 (Casey & Murphy, 2014; Stephan et al., 2018). There are advantages of this method for *plwd*. There is less pressure on participants to contribute than in an interview (Hubbard et al., 2003) and memories may be recalled by *plwd* as other participants share their experiences (Bamford & Bruce, 2002).

There are limitations that require consideration when completing focus groups. On a practical level they can be challenging to arrange (Wilkinson, 2015). Some participants may dominate the process, and parallel conversations may happen; participants may engage in storytelling and there are challenges interpreting data (Bamford & Bruce, 2002). *Plwd* may also face communication challenges. Focus groups may involve interviewer effects; the identity of the researcher may affect the participants' willingness to be open and honest, and to provide data (Denscombe, 2014).

Despite the limitations of focus groups, they were considered appropriate for this study. They enabled the researcher to gain the views of all participants simultaneously and were straightforward to arrange as the participants were already sitting together in a group for the activities. The logistics of completing a number of individual interviews in the care home setting would be challenging around the daily schedule. The focus groups for care home staff were more challenging to arrange, however were still completed with less disruption for the care home operation than individual interviews. The groups provided a supportive and natural environment in which all participants, but particularly those *plwd* felt comfortable to express their views. They enabled the researcher to explore the views of the small sample involved in this study with the use of pictorial prompts and pictures of the prepared food.

There are limitations of data gathered during focus groups that are acknowledged. The samples are small and therefore arguably not representative however this research was purely seeking the views of the participants in the small study and did not aim to make universal claims. Data gathered is limited for drawing comparisons between groups although studies have been completed using this approach (Wilkinson, 2015) which was adopted for this study.

To address potential interviewer effects associated with focus groups the researcher worked with participants to build trusting relationships, and adopted an 'unconventional' approach to interviewing in which they shared their experiences and emotions, as discussed by Denscombe (2014). This was considered appropriate as the researcher was familiar with the participants and had been involved in all aspects of the research. Any experiences or emotions shared were related to the research.

Topic guides were designed for both groups of participants (see Appendices 8 and 9). Those for participants were short as *plwd* had already engaged in activities for approximately an hour. Straightforward and unambiguous questions were included around the areas of; their impressions of the intervention, the impact of the intervention and the likelihood of them becoming involved in similar interventions in the future. The questions focused on emotions and feeling rather than 'matters of fact' as these strategies have been used successfully in previous research with *plwd* (Kirkland et al., 2014). The topic guides for care home staff were designed to last about an hour and included background questions which explored participants' previous involvement with activities in the care home, questions about the sustainability of the intervention in addition to their impression of the intervention, and the impact that they felt it had on residents.

4.4.4 Additional information sheets

Blank information sheets (see Appendix 10) were provided to all residents and students involved in the focus groups, at the end, as the context of the research meant that there was little opportunity for participants to make personal disclosures or comments without staff hearing.

In sum, this section has discussed the methods used in this study, the rationale for using them, and their strengths and limitations.

4.5 ETHICAL CONSIDERATIONS AND PROCESS

4.5.1 Ethical considerations

Approximately 80% of care home residents are living with dementia (Prince et al., 2014), it is important to hear their voices. Although 'the involvement of people living with dementia as research participants is of paramount importance and recognised as a significant contribution to society' (Alzheimer Europe, 2011, p.1), completing research in care homes with residents, including those living with dementia can be challenging for researchers.

4.5.2 The care home environment

In accordance with British Psychological Society (BPS) principles the researcher ‘considered all research from the standpoint of the research participants, and any other persons…. who may be potentially affected by the research’ (2014, p.11). Therefore, residents in the homes, who may be affected by the research, were advised of it, and families of residents. Posters were produced for display in public areas within the residential home, which invited people to an information event.

To address any concerns regarding privacy, visits by the research team and students to the care home was limited to public areas. All members of the research team and students attended an induction event provided by the care home management in which they were made aware of any relevant policies and procedures within the home. Care home staff were present during every visit that the research team made to the care home. No member of the research team or any student was ever alone with residents.

‘Emotional danger’ is inherent in research in care homes (Lee-Treweek, 2000). Research in care homes can be ‘emotionally and ethically demanding’ for researchers; the care home environment may present the researcher with a ‘view into the future’ and may test their values and beliefs about ageing (Luff, Laybourne et al., 2015; Luff, Ferreira et al., 2015). The researcher may witness, or become aware during the research, of care practices which appear unacceptable. To address this, the researcher kept a reflective diary (see Appendix 11) as suggested by Silverman (2000). The intervention was well planned, with regular supervision. If the researcher experienced any problems plans were in place that they would report them directly to the supervisory team. The researcher also had access to a counselling service at the university.

It was recognised that students may be unfamiliar with a care home environment which may present them with a ‘view into the future’ and test their values and beliefs about ageing (Luff, Furreira et al., 2015). The research team and care home staff accompanied students at all times in the care home, and were available to provide support. Students were also provided with details of further services which provide emotional support to young people on the debrief form (see Appendix 12).

4.5.2.1 Challenges of research with people living with dementia

There are two key challenges discussed in this area, one relating to protection from risk, the other relating to the challenges of informed consent and capacity. The BPS (2016, p.13) defines risk as ‘the potential physical or psychological harm, discomfort or stress to human participants that a research project may generate’. The aim with *plwd* should be to keep risks to a minimum. Research involving participants who lack capacity would normally be considered as more than minimal risk (BPS, 2013, p.13). There has been much debate around the term ‘minimal risk’ in relation to the inclusion of *plwd* in research. Minimal risk research is defined by Weijer (2008, p.359) as ‘the probability and magnitude of harm is no greater than that encountered in the daily lives of all (or the greater majority) of persons in the population from which research subjects are to be recruited’. However, Alzheimer Europe (2011) warn that an overemphasis on possible harm may lead to the possible benefits of participation being overlooked. The benefits, for *plwd* who of being included in research which has been designed in a ‘safe context’ usually ‘far outweigh the risks’ (Hellstrom et al., 2007, p.608). The communication and understanding of the risks and benefits of engaging in any research with human participants is part of the informed consent process. Here lies the challenge with issues of capacity, it is incumbent on the researcher to ensure that these are explained and understood.

4.5.2.2 Informed consent options

Several options for informed consent are discussed in the literature:

Initial consent: this also recognises that recruiting *plwd* often involves gatekeepers, particularly in residential settings (Hellstrom et al., 2007). There are limitations to this, as gatekeepers may identify suitable participants based on their relationship with them, and their judgement and perception of the research (Hellstrom et al, 2007).

Proxy as default: proxy consent has historically been sought for *plwd*, based on the assumption that they do not have the capacity to provide informed consent (Beattie et al., 2018), particularly in residential care settings (Hubbard et al., 2003). Proxy consent is an option which is regularly taken to protect *plwd* from being harmed or upset during the research process however researchers should seek ways to mitigate any potential risk rather than excluding *plwd* from research (Alzheimer Europe, 2011; Hellstrom et al., 2007).

However, whilst the question of capacity, which lies at the heart of informed consent is complex, it is not determined purely by cognitive ability and deciding whether an individual has capacity to engage in research purely based on a cognitive test can deny an individual autonomy (Beattie et al., 2018). Several strategies have been proposed to address this challenge.

Assess capacity - Proxy if capacity cannot be established: researchers need to adhere to the Mental Capacity Act (MCA) (2005) which states that a person is unable to make a decision if they cannot 'understand the information relevant to the decision, retain that information, and use or weigh up that information as part of the process of making the decision, or communicate their decision (whether by talking, sign language, or another means' (UK Government, 2005, section 3). However, capacity is not all encompassing: an individual may be able to make one decision but not another; 'an individual's capacity is a point along a continuum and can vary depending on their daily performance and the complexity of the decision that the individual must make' (Cacchione, 2011, p.224). The MCA states that a person should be considered as having capacity to make a decision until it is established that they do not, that person should be supported to make that decision. If it is established that an individual does not have capacity to make a decision, any decisions made on their behalf should be in their best interests (UK Government, 2005, part 1).

Whilst aimed at protecting the *plwd* from harm proxy consent may be sought almost ritualistically, and *plwd* may not be included in the consent process until the proxy consent has been received (Dewing, 2007, p.60). Proxy consent may not reflect the choice and desires of participants, and *plwd* may object to it (Hubbard et al., 2003).

There are therefore two guiding, and potentially conflicting principles, to consider when gaining informed consent from *plwd* in research; autonomy and protection; researchers have to consider their responsibility of care to the participant, and protect the rights of participants. The BPS states that 'a reasoned balance should be struck between protecting participants and recognising their agency and capacity' (2014, p.9) and that:

> 'In the specific case of persons lacking capacity to give valid consent, willing and fully informed consent for participation should be sought from a legally responsible proxy; and research without consent from a person should normally only occur if the research activity is considered to provide direct benefit to that person' (BPS, 2014, p.32).

However informed consent does not necessarily require contact with the person with dementia until after proxy consent for the research has been given; although, the original intention of proxies is to protect the person from harm, the emphasis on 'right doing' and duty has inconsequence, a direct focus on the researcher and not the person with dementia (Dewing, 2007, p.60).

One way of assessing capacity is through on-going consent. Consent should be an on-going process and that a fuller appreciation of the research and the nature of participation will often become more apparent to participants during the course of their involvement with the research (BPS, 2014, p.21).

If capacity cannot be established Slaughter et al. (2007) suggest that researchers should gain informed consent from authorised representatives and assent with *plwd*. Black et al. (2010) suggest that, when proxy consent is sought the participants' ability to provide assent should be determined. Assent can be expressed clearly and verbally, or judged on behaviour, non-verbally (Black et al., 2014). Abilities required are 'the ability to express or indicate a meaningful choice' and 'Many individuals with dementia who are unable to express their willingness verbally could do so behaviourally' (Black et al., 2010, p.4). The capacity to assent is different from the capacity to give informed consent in that informed consent requires that individuals have the capacity to understand the research protocol to decide whether they voluntarily agree to participate in a study (Black et al., 2008). It is important to watch for dissent: 'a verbal or non-verbal indication of unwillingness to participate in study procedures' (Black et al., 2010, p.50).

Dewing (2007) suggest that 'for persons with a dementia, informed consent becomes increasingly redundant and consequently exclusionary to them as persons', she recommends process consent to support *plwd* to consent to research, thus supporting the premise of the MCA (2005). The process described here was adopted for the current study:

1. Background and preparation: clarify permission to access *plwd* with gatekeepers, this is not proxy consent. Find out what wellbeing looks like for the individual and approach them when they are in a state of wellbeing.

2. Establishing the basis for consent: previous reports, assessments and opinions should be considered. Adapted consent forms could be used. If capacity does not exist 'to what degree the person can make choices for themselves' (Dewing, 2007, p.62), at this stage there is less emphasis on the retention of information 'and more about how it feels in broad terms. This must be revisited regularly and is not informed consent.

3. Initial consent: provide information; adapted information sheets could be used, using single key words, with or without pictures. Props could be used as an alternative.

4. On-going consent monitoring: This is revisited on every occasion, thus a process. Asking someone else to validate the process is good practice.

5. Feedback and support: if the researcher has any concerns for the *plwd* or believes that they need support back to their day-to-day life this should be provided to gatekeeper, ideally with the agreement of the participant.

The ethical considerations discussed here were taken into account in the current study. An overview of the ethical procedure follows.

4.5.3 Ethical procedure

The research adhered to the ethical codes of the BPS (2016), and the British Society of Gerontology (2012). The study procedures described below were given full ethical approval by Swansea University CHHS/CIA/Ethics universities Concordat (February 2017). Through this process, the research design and documentation (including recruitment material, information sheets, consent forms, interview schedules, DCM procedures, questionnaires) were reviewed and approved for use in the thesis.

The researcher read in depth about the challenges relating to research in care homes involving residents with dementia, prior to the research, which is discussed in the previous section. They have personal experience of caregiving for a family member living with dementia and liaised closely with care home managers and staff about the research design, and how to effectively support the residents living with dementia. It was recognised that even with good planning unforeseen issues would arise and that there would be issues that required resolving during the fieldwork (Hubbard et al., 2003). As suggested by Hubbard et al. (2003) the researcher continually reflected on the fieldwork process with the use of a research diary, an extract can be seen in Appendix 11). Any issues that arose during the fieldwork were addressed by the researcher and care home staff who were present continuously throughout the research. This following section discusses the key ethical considerations relating to the study, and how they were addressed.

4.5.3.1 Participant recruitment

The recruitment process involved identifying care homes as suitable research sites, and then identifying and recruiting staff, residents and students as study participants.

Care homes: the supervisor for this project identified and made initial contact with potential research sites from already formed contacts in the care sector in Wales. Once this initial contact was made, and potential interest has been indicated, the researcher met with the care home managers to discuss and agree the details of the intervention.

Staff and care home residents: initial contact with residents, their families, and staff was made by care home management who acted as gatekeepers (Hellstrom et al., 2007). The care home management talked to staff, family and residents about the research and handed out research packs, containing information sheets (see Appendices 13, 14 & 15), and consent forms (see Appendices 16, 17, 18 & 19), to people who indicated an interest. The researcher was in constant contact with the care home and visited once a week for four weeks to talk to any interested parties, and answer any questions that people had about the research. The care homes also displayed posters (see Appendix 20), provided by the researcher, with details of a meeting which the researcher had planned for residents, carers and family members who wished to attend. At this meeting the researcher planned to discuss details of the intervention/research, and hand out information sheets and consent forms to residents and/or family members.

Members of care home staff were selected for the focus groups from the members of staff that had been on duty at the times the intervention was implemented, and had consequently supported the intervention. Members of staff who had supported at least half of the intervention sessions were eligible to join the focus group.

Students: care home management and staff were asked whether they knew of any groups of young people and/or schools, colleges or universities in the local area. The care home did not have any preformed connections therefore the researcher explored suitable possibilities in Swansea University. All students at Swansea University had the opportunity to participate in the research as an advert was posted on the Swansea Employment Academy website. Additionally, e-mails were sent to all students of the Psychology department. The researcher placed an advert on the employability website and sent e-mails out to a number of departments in the university after agreeing permission with the head of the department (see Appendix 21); students were invited to contact the researcher if they were interested in the research.

4.5.3.2 The inclusion/exclusion criteria

The inclusion/exclusion criteria for each participant group are described in Table 9 below.

Table 9: *The inclusion/exclusion criteria for participant groups*

Participant group	Inclusion criteria	Exclusion criteria
Paid carers	Paid carers who were employed by the chosen care home at the time of the intervention, and had supported participants during at least 2 of the activity sessions.	
Residents	Residents of the care home that were identified by the gatekeeper as being suitable and likely to enjoy the intervention	Individuals who are unable to communicate verbally in English
Plwd	Residents of the care home that had a diagnosis of dementia and were identified by the gatekeeper as being suitable and likely to enjoy the intervention	People who are unable to communicate verbally in English If informed consent could not be obtained from residents with dementia or their family members, they were not included
Students	Male and female volunteers; aged 16-24 recruited from local groups/schools/colleges/university	

The study aimed to be as inclusive as possible within the limited participant base. Care home staff who had supported at least 2 of the intervention sessions were included in the focus groups; which meant that they had a good opportunity to observe the participants during the intervention. The care home managers acted as gatekeepers; their knowledge of the residents meant that they were in the best position to identify residents that were able to join in the activities, and were likely to enjoy them. The only specified exclusion criteria were; if the resident was unable to communicate verbally in English, or if informed consent could not be gained from residents living with dementia, or their family members. The inclusion criteria for students were based on age, between 16 and 24, as this meant that they were old enough to provide informed consent themselves, and young enough to satisfy the description of the younger generation in IG studies provided by Hatton-Yeo (2006) of under 25.

4.5.3.3 Informed consent

Written informed consent was collected from all participants and/or family members who were fully informed about all aspects of the study through the use of study information sheets (see Appendices 13-15). Participants were given time to process and reflect on the information before deciding whether they agreed to participate in the study. Care home managers were given a consent form which required them to agree that their establishment could participate in the research and that they agreed to be gate keepers (Appendix 22).

The consent process for residents and their families was facilitated by care home staff and the manager, by acting as gatekeepers and providing information sheets and informed consent forms to residents and their families. Gatekeepers approached residents who were able to consent, and family members of residents who were unable to consent to complete initial discussions regarding the research, provide information sheets and consent forms.

For care home staff who were invited to participate in the focus groups, the researcher provided a carer information sheet (Appendix 13) and consent form (Appendix 16) prior to the beginning of data collection. Time was spent explaining the nature of the intervention and what it would mean to them if they agreed to participate.

The researcher gained permission from the care home manager to speak to residents; and visited the care home on a weekly basis for four weeks prior to the intervention to do this. The staff acted in the best interests of the resident; they knew the residents well and could gauge whether they would like to join the intervention. Care home staff spoke to residents and family members as they visited their relatives.

To ensure that those residents living with dementia were not excluded from the recruitment process and were given as much information as possible in an appropriately designed format, information sheets and posters were designed using clear and accessible language, pictures, and short words and sentences; the use of technical terms was avoided. Residents were provided with the opportunity to meet with the researcher where information was provided verbally, and residents had the opportunity to ask questions. Hence, the researcher aimed to ensure that *plwd* had; 'genuine choice and an understanding of the purpose of the study and how the data will be used' (Bamford & Bruce, 2002, p.139). If the resident living with dementia was able to provide written consent, this was gained at two points during the study: before the activities began and before the focus group.

I discussed with the care home manager and staff whether they considered a given participant was able to consent for themselves. Where the capacity to consent could not be established the researcher adopted the following process which incorporated proxy consent, alongside some aspects of process consent and assent. Initial consent was sought from family members. I also ensured a process of continual consent which involved assent 'a verbal agreement to participate based on less than full understanding' (Slaughter et al., 2007, p.32). The I spoke to *plwd* before each activity session and the focus groups to remind them of what would happen during the session, and to ensure that they wanted to be involved; a written record of this assent was kept by the researcher in a research diary. Paid carers were present during the sessions and focus groups who were familiar with the ability of residents to indicate their preferences, verbally or non-verbally. Care staff were alert to any signs that the residents were not comfortable and may not have wished to continue; myself and staff were sensitive to participants verbal and nonverbal behaviour. In this was any signs of dissent 'a verbal or non-verbal indication of unwillingness to participate in study procedures' (Black et al., 2010, p.5) were respected; if participants showed signs of dissent care home staff supported them to leave the research and return to the communal lounge or their private room.

Gaining consent from students: once I received e-mails from interested student's, information sheets (see Appendix 23) were sent with an invitation to meet if they were still interested in participating after they had read the information sheet. At the meeting I explained all aspects of the research, handed out informed consent sheets (see Appendix 24) and asked the students to return the consent forms once they had considered the information that they had been provided. Students returned the consent forms by hand once completed.

4.5.3.4 Confidentiality and anonymity

The procedures undertaken to ensure the anonymity and confidentiality of participants and their data involved several steps. The names of care homes involved in the research were omitted in the write up of this study. No demographic data of residents age or gender was collected or recorded. Care home managers were asked, and agreed to keep details of residents that engaged in the research anonymous. The students involved in the research were Psychology students who were familiar with the BPS ethical requirements for confidentiality in research; they were reminded of the importance of this during the awareness session provided to them by the researcher before the intervention began.

Participants were told on the study information sheet that all data that they provided would be kept strictly confidential unless there were significant concerns about their safety or the safety of others. The content of the focus groups in this study focused on participant experiences of the intervention therefore did not ask participants to provide sensitive information. However, ground rules were set at the beginning of focus groups to ensure that personal details and sensitive information was not shared outside of the group. Participants were requested to 'respect and preserve the confidentiality of others' as suggested by Wilkinson (2015) but were reminded that it could not be guaranteed that other participants would not discuss their responses outside the focus group. Bamford and Bryce (2002) suggest that *plwd* may forget where they learned the information and that they had agreed to a level of confidentiality.

To maintain confidentiality participants names and identifying information were changed for data presentation. Individual participant numbers were used on any data collected including DCM data sheets and student questionnaires. The data collected was handled in an anonymous form which involved giving individual participants a number instead of using their name or initials. During focus group transcription personal information was removed and names of participants were coded/changed to maintain anonymity. Other names in the focus groups were changed too. Information contained within the study information sheet and the consent form ensured that the participants were aware of what was intended to do with the data after it had been anonymised. After completion of the study no participant data were able to be identified to the individual.

Participants were informed that the focus groups would be audio recorded and that the audio recordings and transcriptions would be anonymised, securely stored and then destroyed. Data from the focus group recordings were deleted from the recorder within 48 hours of the focus group taking place and were uploaded to a password protected computer. Only the researcher had access to this. Once transcribed the recordings were deleted permanently from the computer. Participant numbers, written consent forms, the research diary where assent was recorded and study data were held separately in a secure place, within the research office at the university, until the research was completed. In line with Swansea University guidelines, all data will be kept ten years after the final thesis is submitted and disposed of securely after this time.

4.5.3.5 Potential risks and strategies to minimise the risks

Though the study was minimal risk and there was the potential for participants to benefit from their involvement with the intervention it was recognised that there were potential risks to participants to taking part in the study.

Potential risk for staff: there was the possibility that paid carers felt obliged to complete the focus group. To address this, it was made clear in the study information sheet that participation was completely voluntary, that participants did not have to answer any questions that they did not want to, and could withdraw at any time without giving a reason.

Potential risks for residents and students**:** there was the potential of Health & Safety issues arising from preparing and sharing food, and participants with food allergies for example. To minimise the risk the research team liaised closely with the care home management and staff, ensuring that the intervention was designed and implemented to adhere to the Health and Safety policies, which were in place. Protective gloves and aprons were worn by the activity facilitator and all participants. The activities and utensils required to complete the activities were carefully considered and chosen; none of the activities required cooking. Care staff and students were in attendance at each session to ensure the safety of *plwd* during the activities. Information was sought from participants, and care home staff regarding individual food preferences, eating and drinking difficulties, and allergies.

Potential risks for residents living with dementia: there was the potential to affect the self-esteem of residents living with dementia if they: were unable to complete the intervention, were asked questions during the focus groups that they did not understand or were unable to remember, or perceived that they were being judged or assessed during the observation. There was also the potential to create stress and confusion if instructions were too complex, or groups were too big. To minimise these risks participants were told in advance, and at the start of each activity session and focus group what would happen. They were told of the study aims and assured that the research was not assessing them but was focused on activities that care home residents might enjoy. The language used throughout the research project was carefully considered, for example consideration was given to whether to use terms such as ’dementia’ or ‘issues with memory’ (Hellstrom et al., 2007). Although the term dementia was included on information sheets the researcher did not focus on the diagnosis if participants did not mention it themselves, as residents may be unaware of their diagnosis and this information may harm the participant. Throughout the research the researcher judged ‘what to do from individual to individual, from situation to situation, in an open dialogue with care staff,’ who know the participants, as suggested by Heggestad et al. (2012). The intervention was carefully designed to suit the abilities of the residents, with input from care staff. The research involved input from an OT who supported the researcher to assess the suitability of the activities for the abilities of residents, using the PAL occupational profile (Pool, 2012), which is discussed full in Chapter 5.

Sensitive topics may be discussed during the activities or the focus groups which have the potential to create distress for participants. To minimise these risks participants were reminded that they could leave at any time without providing a reason. Standardised and psychometrically robust measures were carefully selected for the student questionnaires based upon their sensitivity (Appendix 7). Questions for the focus groups were carefully selected based upon their sensitivity (see interview schedules; Appendices 8 & 9). If any signs of distress were observed in residents, they were asked whether they would like to leave, and if so, were accompanied by a carer who looked after their well-being. If any signs of distress were observed in students the researcher or residential staff would assure them that they were free to leave, would accompany them if they choose to do so, and would look after their well- being. The student would be offered comfort and reassurance by the researcher or a member of the residential staff.

4.6 CHAPTER SUMMARY

This chapter described the methodological and ethical principles underlying this thesis. The overall study design was discussed including the framework and strategies used to evaluate the intervention, alongside the ethical principles guiding the research. First the ontological and epistemological foundations that influenced the use of a MM research approach guided by a pragmatic paradigm were outlined. Pragmatism is concerned with problems and how to solve them; the focus of inquiry is on situations, actions, and consequences, therefore aligned with the aims of this study. In this thesis, an experimental MM framework guided by pragmatism was used as it provided the researcher with the opportunity to explore the implementation and outcomes of the intervention from a number of perspectives; care home staff, residents, and students. The data collection and analysis plan was outlined before discussion of research methods used in data collection. Each method used was discussed and critiqued, and the rationale underpinning the choice of each method was outlined. Finally, the ethical issues that were considered and addressed in the design and implementation of the research methods were discussed. The following chapter will outline the process completed to implement the intervention, gather data, and complete the analyses.

5 CHAPTER 5: THE STEPS UNDERTAKEN TO IMPLEMENT THE INTERVENTION, GATHER DATA, AND COMPLETE THE ANALYSES

The aim of this chapter is to outline the process that was followed to implement the intervention, gather data and complete the analyses. The chapter starts by describing the steps that were taken to recruit an activity facilitator and an O/T to support the project, identify care homes, and develop relationships with all parties which facilitated the development and completion of the intervention. This is followed with a section which describes the intervention implementation; the extent to which the activities provided matched the protocol prepared, and the attendance of participants during the intervention. The chapter concludes by outlining the plans which were developed to gather and analyse the data.

5.1 DETAILS OF RESEARCH SITES AND STUDY PARTICIPANTS

The intervention was completed twice; initially with residents living with dementia paired with residents unaffected by dementia, and subsequently with *plwd* paired with students. Both interventions were completed over a four-week period within dementia care units in two different care homes, both operated by the same care home group in South Wales.

The research design comprised of some elements of natural enquiry as outlined in Chapter 4, and therefore required the researcher to develop an intimate knowledge of the field site, the participants and the residential setting in which they lived (Armstrong & Salik 2010). The research site was effectively one where people both live and work, and the researcher spent significant amounts of time with the participants. Lincoln and Guba (1985) state that the value of a research study is determined by its trustworthiness, the four components of which they see as: credibility, transferability, dependability, and confirmability. They also refer to 'thick description' as essential in ensuring that the complexities of a given research context are clearly explained (p, 214), and also as a means of assessing whether the findings of the study will be transferable to other settings. If the description is sufficiently 'thick' the reader should feel as though they are actually in the setting. The following section aims to bring the residents and the setting in which this research was completed, to life, as a way of contextualising the findings, enabling “transparency” (Armstrong & Salik, 2010), and allowing the reader to assess the transferability of the findings (Lincoln & Guba, 1985).

The intervention was completed in two different care homes, both were managed by the same care home provider, so with little difference in the way they operated. The following section will discuss these, starting with a general description of the location and the physical environment of the homes, which will be followed by description of a number of areas which are pertinent to the study including staffing levels, activity provision, the gardens, and the provision of food and drink.

Both of the residential homes were situated on the outskirts of large villages, and generally serve the local population. They are purpose built, have two floors, and provide care and accommodation for adults over 65, based on smaller group living. Accommodation is divided into communities or suites which house small groups of residents, and there is a communal lounge where all residents can gather. A number of suites within each home are dedicated to providing care and accommodation for *plwd*. The residential home which hosted the Intergenerational intervention is a little more modern, and larger than the home which hosted the resident only intervention, providing care and accommodation for up to 65 older adults, compared to forty older adults, and each suite accommodates up to 10 residents, compared to eight.

The intervention was completed in one of the dementia suites at both homes. Each suite was homely, comfortable and safe, and consisted of a communal kitchenette/dining/lounge area with bedrooms located around this area; the suites are accessed via a door with a keypad. The activities were completed at the dining table in the communal kitchen/dining area. Although these areas were configured slightly differently in each home, they were well suited for the activities; there were sufficient chairs for all participants and room around the table for care home staff and the research team to deliver, observe and support the activities from an appropriate distance. Staff of the care home, the facilitator, and myself were in close enough proximity to participants to act quickly should the need arise, but far enough away to prevent intrusion. Staff and residents who did not engage in the activities were able to continue with their daily lives, sitting at other chairs or tables in the dining area or relaxing in the lounge.

It had been established at the outset with the respective care home managers that there would be adequate staff present to enable them to support the intervention and its participants and this was the case; a minimum of two staff were consistently present during the intervention, with additional staff visiting to assist with daily tasks such as laundry. A number of residents and staff had lived or worked at the homes for many years, so relationships between them were warm and friendly. This was important for the intervention, as staff were able to inform the research team about the likes and dislikes of the residents and whether they were comfortable and at ease. Each care home offered residents a varied programme of activities, some offered in the communal lounge, others delivered by staff in the individual suites. Residents participating in the research would therefore have been used to seeing a variety of daily activities and events in their living environment.

Preparing and sharing food was fundamental to the intervention and involved activities of indoor gardening (for example, growing herbs), preparing cold snacks, and eating them together. Each care home provided a suitable environment for these activities as they had accessible gardens which residents could help tend, and one had a potting shed. It became evident during the research that one of the participants in the home which hosted the resident only intervention was regularly involved with the upkeep of the garden. Meals for residents in the care home were home cooked in the kitchen and brought to the suite, and staff could also prepare breakfast and snacks in the kitchenette. Kitchen staff regularly brought snacks to the suite for residents between meals, and care staff regularly offered drinks to the residents. Meals were eaten at the large table in the kitchenette/diner which was where the activities were completed and eaten by the participants, as this was familiar to residents. In sum, the two residential settings selected for the research would have been conducive to encouraging participation in food preparation and sharing activities, as the living environment was "home like" with its garden amenities, cooking routines and opportunities for sharing food.

In one of the care home settings the RO intervention was completed involving a total of six residents, three living with dementia and three unaffected by dementia, all aged over 65. In the other care home setting the IG intervention was completed involving four residents living with dementia all aged over 65 and four Psychology students from

Swansea University aged between 18 and 23. In each care home setting, the intervention was observed by two care home staff each session: four staff attended the focus group. Participant information is shown in Table 10.

Table 10: Demographic data of participants included in the study.

Resident Only Intervention

Participant number	Participant Group	Gender	Age	Ethnicity
1	*Plwd*	Female	65+	White British
2	*Plwd*	Female	65+	White British
3	*Plwd*	Female	65+	White British
4	Resident	Male	65+	White British
5	Resident	Female	65+	White British
6	Resident	Female	65+	White British

Intergenerational Intervention

Participant number	Participant Group	Gender	Age	Ethnicity
9	*Plwd*	Female	65+	White British
10	*Plwd*	Female	65+	White British
11	*Plwd*	Female	65+	White British
12	*Plwd*	Female	65+	White British
13	student	Female	21	White British
14	student	Female	18	White British
15	student	Female	23	White British
16	student	Female	19	White British

5.2 PROJECT PREPARATION

Implementing IG interventions in a care home environment is recognised as complex (Di Bona et al., 2015; Jarrott & Bruno 2003, 2007). An outline of key research activities completed to ensure the smooth running of the intervention can be seen at Appendix 27. The key dates and events will be discussed in the following sections.

5.2.1 Researcher preparation

There were a number of tasks that I completed prior to the intervention to ensure that the research was completed well. DCM training and achieving Inter-rater reliability to use it, familiarisation with the care home environment, and reflection. The following section outlines the nature in which these processes were undertaken and the rationale supporting them.

Practical preparation

I was unfamiliar with DCM at the outset of the research and had little knowledge of care homes, therefore I completed some preparation in both areas before starting the intervention. I completed DCM training at University of Bradford. Inter-rater reliability was achieved subsequently by completing a mapping session with the OT appointed to the team, who is also an approved DCM mapper. I familiarised myself with the care home environment as described in the protocol (see Appendix 3) by visiting the care homes one afternoon a week for four weeks prior to the implementation of each intervention. This was vital for practical and emotional reasons. It was important that I knew what to expect, and began to understand the culture of the home to ensure that my actions were compatible with the care home culture (Dewing, 2009). It was important that I became familiar with the layout of the home and how the spaces were used, which helped me agree the optimum position to deliver the intervention; the kitchen diner of the dementia suite. It was essential for the smooth running of the project that care home managers and staff trusted me and that *plwd* felt comfortable with me in their home, so that they could engage freely with the intervention whilst I observed. During these pre-intervention visits I started to get to know the care staff and participants, which enabled me to communicate effectively with the care staff to ensure smooth running of the intervention, and with participants which enabled me to gauge what they might, or might not enjoy.

I also considered how I would be seen by others as suggested by Dewing (2009), in this case care staff, participants and residents. I wanted to fit in whilst appearing friendly, approachable and efficient. I chose my outfit carefully, a dark pair of trousers with a white top which I believed to be the right level of formality. I wore the same clothes each time I visited the care home for consistency, which I felt would be advantageous for the participants who might begin to recognise me, and accept my presence. It was also important to prepare myself on an emotional level, as I would be 'bearing witness' to the experience of older adults (Dewing, 2009) and be in an environment which I might find myself in as I age, which has the potential to invoke sadness and therefore affect my performance as a researcher within the care home. As a 50+-year-old woman I periodically contemplate retirement and how I would like to live in my later years. At the start of this project, I had little experience of care homes, which I reflected on.

Reflection is an integral part of qualitative research; in care home research it is vital (Brown, 2011; Dewing, 2009). I recognised at the outset that I played a key role in the research process. In collaboration with my supervisor, the research team, and care home staff I had designed and planned the intervention, would manage the implementation of the intervention, and gather and analyse data. Observation and fieldwork were fundamental to this study. As suggested by Dunscombe (2014, p.89) this all meant that my 'identity, values and beliefs become part of the equation', I therefore needed to reflect on the way that my experiences, beliefs, and values may have shaped the research. Lincoln and Guba (1985) suggest that keeping a reflexive diary is one of four checks and balances that researchers can use to ensure 'trustworthiness 'alongside; member checks, debriefing by peers, triangulation, prolonged engagement and persistent observation. Dunscombe (2014) states that it is not enough for researchers simply to reflect, but that these reflections need to be portrayed publicly if they are to support the research outcomes; the reader needs to be supplied with these insights. What exactly is shared is a matter of judgement but as a minimum Dunscombe (2014) suggests that researchers share their: personal beliefs relating to the topic, personal interests in the area of investigation, and their personal experience linked to the research topic. The following section aims to do this.

Personal beliefs relating to the topic: Dewing (2009) suggests that a reflexive approach is vital throughout the research process in care homes, and that before researchers begin, they reflect on their views and where they originated from in a number of areas. The areas that Dewing (2009) suggests researchers reflect on are; care homes, residents and their families, and carers. Prior to this research my perception of care homes was one of places where older adults move to spend their final years, typically watching television in a communal lounge with other residents. I have visited family members in care homes; however, these were short visits over brief periods, therefore much of my views and perceptions of life in care homes have been influenced by anecdotal stories, evidence provided by others, and media articles which typically focus on poor care. I believed that care homes meet a need for those who need care which loved ones may be unable to provide, but that it is better to stay at home; my parents had made it clear to me throughout my life that they did not want to live in a care home. This resulted in an assumption that residents, and families of residents, had not decided on a move to a care out of choice, but necessity.

Personal interests in the area of investigation: I want to ensure good care in care homes for current and future residents, plus my family and myself. At the start of this research, I had been caring for a family member living with dementia for five years with the aim of enabling them to remain living at home, in line with their wishes. I have been doing this with the recognition that there may come a time when my loved one requires more support than can be provided at home and that a move into residential care may be optimum. I have a family member who is an Occupational Therapist who has offered suggestions on how I could improve the environment in my home to ensure that the environment is optimum for an individual living with dementia. I have engaged in this process enthusiastically and been impressed by the benefits that I have witnessed. I have learned about improving the environment in my own home and was interested to see what could be done to improve the lives of people with dementia living in a care home.

On a personal basis, I am less than 10 years away from retirement, therefore I periodically contemplate how I would like to live in my later years, including the type of care home which I would, or would not, like should the need arise. I would hope that if I live in a care home that I would be able to have some choice about how I spent my time; that I could enjoy some quiet, private time and have some fun too. I am therefore very committed to a good provision of care in care homes which incorporate the opportunity for fun and engagement.

Personal experience linked to research topic: During the course of my studies in Psychology I learned about dementia; this academic knowledge has been complemented by the practical knowledge that I have gained whilst caring for a loved one who is living with the condition. All of this was useful when designing and completing the research. For example, from my personal experience I recognised that people living with dementia are individuals who have different experiences, however was aware of strategies that could aid communication, such as using short simple sentences and pictures to support words, and based research materials on this strategy.

Research experience/views: I had some relevant research experience prior to this thesis which included; an undergraduate dissertation which was based in a work organization, and an MPhil which explored stress experienced aby adolescents living with Down syndrome, who therefore experienced a level of cognitive challenge. I had also acted as a research assistant on two research projects which evaluated interventions for participants who lived with chronic health conditions. These projects had used a mixed methods approach, which involved interviews, focus groups, and questionnaires.

During my undergraduate studies I learned about Psychology as a Science, and positivism which prizes objectivism (in the purest form), alongside counselling which has a philosophical base. This provided me with an understanding of differing viewpoints of objective/subjective and nuances around this. A positivist approach purports that the researcher and the researched are separate entities, and that it is essential for the researcher to keep a 'discreet distance' from the people in the research to eliminate bias (Lincoln & Guba 1985, p.3). Positivism also suggests that: 'experiments can be designed meticulously enough so that no one can influence the outcome' (Lincoln & Guba 1985, p.3). I realised early in my research career that: 'objectivity in it's pure form is an unattainable state' as suggested by (Lincoln & Guba, 1985 p.108.,). In this thesis It was unrealistic to believe that as a researcher I could maintain a distance from the participants that I was studying as building good relationships was a key element of this project, and by it's nature required personal investment from me in terms of sharing thoughts, recognizing emotions, and adapting to each participant, for example.

As I started to conduct research, I aimed to achieve a level of impartiality, whilst accepting that my personal experiences, thoughts, and feelings would affect the research process. As posited by Lincoln and Guba (1985) subjective or objective are not the only options. Schwartz & Ogilvy (1979) suggest that whilst objective suggests a distance and subjective suggests a personal view, there is another option which is based on perspective. What I aimed to do in this thesis was to observe and report my observations honestly, and thus provide; a ‘view at a distance from a particular focus’ as suggested by Schwartz & Ogilvy (1979, p.55) which was trustworthy according to four criteria outlined by Lincoln & Guba, 1985): credibility, transferability, dependability, and confirmability.

Research design: I chose mixed methods as it is a way of designing research which recognises both the need for more “objective” empirical measurement, combined with the need for an approach which captures the socially constructed nature of reality – and hence allows for questioning of “objectivity”. Adopting a pragmatist approach, I carefully constructed this study which involved a mix of data collection tools, some qualitative (focus groups), some quantitative (scales) and DCM which involves quantitative and quantitative data collection and analysis.

One of my aims in this study was to give the participants living with dementia a voice; whilst DCM aims to represent the experience of *plwd* from their perspective, it is an observational data collection tool, the data is collected through my eyes, therefore represents what I believed to be the perspective of participants. There is no way of knowing the reality of participant stories (which no one can ever know), however this is more challenging when working with *plwd* as their communication skills may have been affected by the condition, which may prevent them from discussing their experiences. Recognising that there is no way that I can ever truly know how a participant experiences something, and that my observations of another are subjective I sought additional data. I gathered data from a number of perspectives: residents, staff and students, therefore: ‘balancing multiple perspectives to constrain bias’ as posited by Schwartz and Ogilvy (cited in Lincoln & Guba 1985, p65).

To conclude; this section has discussed the preparation that I undertook to plan and deliver this project. It has outlined my personal experiences, values and beliefs which cannot be separated from the project. Realistically, what I aimed for was to: be impartial to the outcome of the research, acknowledging my own preconceptions, and to operate in as unbiased and value-free way as possible. I tried to do this by having ‘debrief’ sessions with the activity facilitator after each activity session, keeping a reflexive diary throughout the study, and attending regular supervision sessions. I sought guidance from professionals and care home staff regarding the suitability of activities for *plwd*, and designed the research questions to focus on the view of participants about the intervention therefore kept the focus on the phenomena under study.

5.2.2 Identifying two care homes

Buckwalter et al. (2009) suggested that 10 factors are assessed for each home, not all related to the current study therefore the following were considered: (i) quality of care using current government reports; (ii) bed size of home (potential sample size); (iii) length and time managers had been in their positions in the home. The chosen homes were decided upon for the following reasons: the most recent CCSQ report had indicated that there was a relaxed and friendly atmosphere in the home, and that appropriate humour was regularly used. The report also said that the home provided a good selection of activities including gardening. The researcher felt that this would be an ideal context in which to pilot the intervention. The chosen care home also had the most residential units and the one that had dedicated units for *plwd*, which meant that the potential pool of participants was largest. The manager of the chosen home had also been in post for a longer period of time which suggested more stability with staffing which would be key to the study, and the CCSQ report had stated that staffing levels at the care home were good. This would mean that there would be a likelihood that staff would be available to become engaged with the research and support the intervention.

5.2.3 Recruiting and preparing the research team

The design and implementation of this intervention required that, in addition to my supervisory team, other individuals were required to support the project; an OT, an activities facilitator, students and care home staff.

An OT and an ‘intervention facilitator’ were appointed to the research team. The lead supervisor approached the University and College of Human and Health Sciences to request an Honorary Research Associate contract for the OT to facilitate the validation of certain aspects of the intervention, including use of the PAL (Pool, 2012) tool and DCM validation (inter-rater reliability). The Head of The Dementia Care Training team in Abertawe Bro Morgannwg University Health Board (ABMU) was contacted, and volunteered one of their team. An MSc Psychology student from Swansea

University was appointed as the activity facilitator. The researcher delivered a dementia awareness session to the facilitator, and familiarised them with the proposed activities by running through each session a number of times.

5.2.4 Agreeing the activities

The individual activities incorporated into the intervention were identified by a review of books based on activities in care homes, which was informed by the researcher's personal experiences as a carer for a family member living with dementia; by the professional expertise of an OT appointed to the project and care home managers and staff. Factors which were considered were: consideration of risk, appropriate levels of challenge, and sensory stimulation.

Avoidance of risk has been identified as one of the key barriers to meaningful activity provision (OPCW, 2014) and successful interventions (Lawrence, 2012) in care homes. Risk was therefore a key consideration which informed the choice of individual activities; therefore, activities were chosen which required no cooking. The activities were designed to be flexible, and able to accommodate *plwd* with varying abilities, and differing levels of engagement, which has been identified as important (Lawrence, 2012).

The Pool Activity Level (PAL) instrument (Pool, 2012) was used to ensure that the activities were suitable for the *plwd*. This tool was designed by an OT and is used within the profession to assess the abilities of the individual in nine areas (bathing/washing, getting dressed, eating, contact with others, group work skills, communication skills, practical activities, use of objects, looking at a newspaper/magazine). The instrument identifies the following 4 activity levels, which are outlined in Table 11, and highlights the likely abilities of individuals within each level/profile to engage in activities. An individual may be assessed as having a mixed activity profile.

Table 11: *PAL profiles and their characteristics*

PAL Profile	**Likely Abilities:** ***Likely to be Able to…***
Planned	Engage in activities with an ‘end goal’ and a set process or ‘recipe’
Exploratory	Carry out familiar tasks in familiar surroundings Complete more complex tasks if they are broken down into 2 or 3 smaller steps
Sensory	Carry out complex tasks if they are broken down into simple steps, and demonstrations are provided
Reflex	Make reflex responses to direct sensory stimulation

Note: Table from Pool (2012, p.30)

The PAL (Pool, 2012) is recognised by the College of Occupational Therapists, is accessible to non-professions, and is quick and easy to administer, therefore was considered appropriate for this study. The tool was completed by care home staff in collaboration with the researcher and OT. The appointment of an OT to the research team is discussed in Chapter 6. The profiles of participants included in the intervention were either planned, exploratory, and sensory, or mixed, including aspects of each of the profiles, therefore, activities were designed to reflect this.

The individual activities selected are shown in Table 10. A war time ice cream recipe was chosen as it was believed that this would encourage reminiscence amongst the *plwd*. The ice cream tasting and fruit salad preparation were chosen as they are sensory activities, which involve a variety of colours, smells and tastes. Fruit salad preparation and gardening are included in PAL (Pool, 2012) guidance with strategies to complete the activities with *plwd* assessed as having planned, exploratory, sensory or reflex activity levels, therefore provided a good base on which to plan the activities. Cress planting was chosen as it is easy and quick to grow and fitted within the timescale of data collection, and the activity may be familiar to participants. Sandwich making was chosen so that participants would be able to use the cress that they had grown, which it was felt would make the activity meaningful.

Table 12: *The weekly intervention schedules*

Session	Session topic	Activity
Week 1	Getting to know you	Introductions: making ice cream from a ‘wartime’ recipe
Week 2	Indoor Gardening	Planting cress, and herbs
Week 3	Fruit	Making fruit salad Sharing fruit salad and ‘wartime’ ice-cream
Week 4	Sandwiches	Making and sharing egg & cress sandwiches

Each session included a warm up, the main event and a conclusion as suggested by the College of OTs (Pool, 2012). The warm up activity included introductions and discussion with a variety of reminiscence materials as prompts. Lawrence et al. (2012) found that *plwd* felt that providing an opportunity to reminisce, was a key factor in successful psychosocial interventions in care homes. Talking to and about family gave residents feelings of being connected to their families by reminding residents with dementia of past memories and proving their existence outside of care homes (Han et al., 2016).

5.2.5 Intervention protocol

A protocol was developed after speaking to care home managers about broad ideas to gain agreement for the activities and the implementation, and to guide the process. Once the researcher had produced a draft protocol feedback was sought from; the project supervisor, manager and staff at the residential homes, and the OT appointed to the project. The protocol can be seen at Appendix 3

5.3 IMPLEMENTATION OF THE INTERVENTION

This following section will provide a description of the implementation. In complex interventions process evaluations are generally completed which explore the fidelity, (how well the intervention adhered to the protocol), dose (the amount of intervention contact, and the duration of the intervention) (Conn & Chang, 2016) and reach of the intervention (participants involved). Process evaluations which aim to explain how complex interventions work, …and examine the process through which an intervention generates outcomes’ (UK Government, 2018, p.3) are typically completed by an independent group to eliminate bias (Moore et al., 2015); as this was a PhD study there was no opportunity to do this independently. The following section will therefore discuss the fidelity, dose and reach of the intervention: to provide an understanding of the quantity and quality of the intervention delivered. The aim is to accurately document how the intervention was delivered and illustrate the challenges of undertaking this kind of research in the care home environment.

5.3.1 The quantity and quality of the intervention delivered

Participant characteristics: the participants were ten care home residents aged 65+; seven who were living with dementia, three who were unaffected by dementia, plus four students aged between 19 and 25.

The number of sessions that each participant attended during the RO intervention is shown in Table 13, alongside group totals. As can be seen only one *plwd* attended all four sessions, although they joined one session part way through. Only one resident attended more than one session.

Table

13: *Attendance during the RO intervention*

Participant	Number of sessions attended
1	3 ½ *
2	3
3	2
Group Total for *plwd*	8 ½ of a possible 12
5	3
4 & 6	1
Group total for residents	5 of a possible 12
Overall Attendance	**13 ½ of a possible 24**

* Ppt 1 joined the fourth 4th session in the middle of it

The attendance for each participant in the IG intervention is shown in Table 13, alongside group totals. As can be seen three of the *plwd* attended all four sessions, although one *plwd* left part way through one of the sessions. Three students attended all four sessions.

Table 14: *Attendance during the IG intervention*

Participant	Number of sessions attended
10 & 12	4
9	3 ½
11	2
Group Total for *plwd*	13 ½ of a possible 16
Ppt 13, 14 & 15	4
Ppt 16	3
Group total for students	15 of a possible 16
Overall Attendance	**28 of a possible 32**

*Ppt 9 left one session in the middle of it

Group averages were calculated for the participant attendance, which are shown in Table 15. As can be seen attendance was highest amongst the student group, and lowest amongst the group of residents who were unaffected by dementia. Attendance was higher amongst the *plwd* who engaged in the IG intervention, than *plwd* who engaged in the RO intervention.

Table 15: *Overall attendance rate of participant groups*

Participant group	Attendance rate
Students	93.75%
Plwd in IG intervention	84.73%
Plwd in RO study	70.83%
Residents	41.66%
Overall attendance	75%

Fidelity: the researcher was in attendance at all sessions and monitored the intervention against the protocol that was developed (see Appendix 3). The intervention was delivered according to the protocol with some minor changes; the ice-cream did not set therefore was not served with the fruit salad; the cress did not grow as planned therefore was supplemented with fresh cress. Ham and cheese were offered as alternatives to eggs to add to the sandwiches, as a number of participants said that they did not eat eggs. During the RO intervention carers suggested that the reminiscence picture prompts were included alongside the main activity, as opposed to, prior to it, as participants appeared to lose interest, and were keen to start the activities.

5.4 DATA COLLECTION, PREPARATION AND ANALYSES

5.4.1 Data collection

The focus of the data collection methods was to assess the impact of the intervention on participants, and to assess the practicality of the intervention for a care home setting. Table 16 shows what each tool was measuring, and in which group. Figures 2 and 3 show the points at which the data was gathered during each intervention.

Table 16: *Data collection tools used and their purpose*

Method	Aim	Participant group	Measurement
DCM	To assess the wellbeing of *plwd across time*	*Plwd*	Mood/Engagement
	To explore the behaviours that *plwd* engaged in across time		Behaviour Category Codes
Activity session feedback sheets	To explore the mood of participants after the activity sessions	*plwd* Residents Students	Participant mood
Questionnaires	To evaluate any changes in attitudes towards and comfort with dementia in students	Students	
	Task 1: Dementia Attitude Scale (O'Connor & McFadden (2010)		Changes in knowledge of, and comfort with dementia across time
	Task 2: Phenomenological word task		Changes in the number of words and their nature (positive, negative, neutral) across time
Focus groups	To explore the participants, view of the intervention	*plwd,* residents, and students	Key themes
	To explore the staff views of the intervention, and the likelihood of sustainability	Care home staff	Key themes
Additional information sheets	To gather any additional comments that participants may have that was not collected with previous methods	All participants	

5.4.1.1 Data collection points

Each intervention consisted of four activity sessions, which were delivered for approximately an hour a week, for four weeks. As shown in Figures 2 and 3 DCM was completed at 3 time points each week; before (TP1), during (TP2), and after (TP3) the activity session. Feedback sheets were also completed weekly by participants after each activity session. Two focus groups were held once all four-activity sessions were complete; one focus group for participants of the intervention, the other for care home staff.

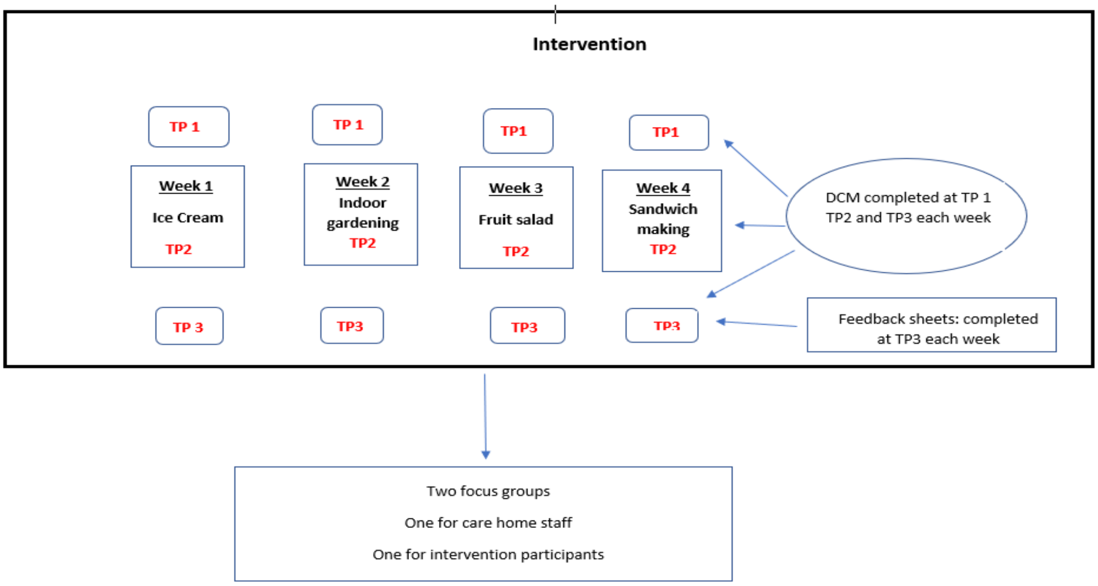

Figure 2: *Data gathered during the RO intervention*

A similar plan was followed for the IG intervention with the addition of a questionnaire which was completed by students at two time points; before and after the IG intervention. This is illustrated in figure 2.

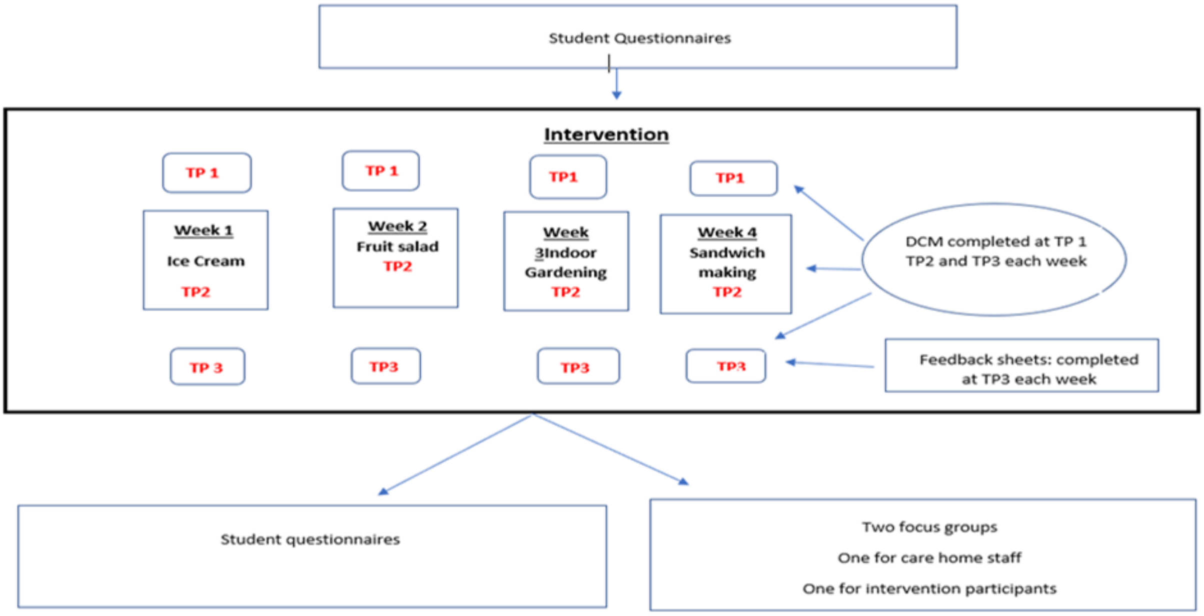

Figure 3: *Data collected during the IG intervention*

5.4.1.2 The process undertaken to complete DCM

To complete DCM, I arrived approximately half an hour before each session was due to start, introduced herself, told the care staff and participants what she was going to do and sat in a chair against the wall quietly watching the participants. The researcher had all DCM manuals/instructions required plus a clipboard and a pen to record her observations.

The DCM process completed during this research was dictated by the protocol provided by University of Bradford (2016) which is outlined below, and accompanied with examples and illustrations of the use of the keys in this thesis. Two tasks were completed during each 5-minute timeframe; identification of the behaviour that the *plwd* engaged in, and an associated ME value.

The first task was to identify a relevant behaviour from a list of 23 BCC’s that are included in the DCM protocol (University of Bradford, 2016) and can be found at Appendix 3. During the study only 12 of the BCC’s were observed, which are outlined in Table 17.

Table 17: *Behaviour Category Codes according to DCM protocol*

Code	General Description of category
A	Interacting with others verbally or otherwise
B	*Being engaged but passively (watching)*
D	Self-care
E	Expressive or creative activities
F	Eating or drinking
G	Reminiscence and life review
K	Walking, standing or moving independently
L	Leisure, fun and recreational activities
N	Sleeping, dozing
O	Displaying attachment to or relating to inanimate objects
P	Receiving practical, physical or personal care
<u>U</u>	<u>Unresponded to</u>
V	Work or work-like activity

DCM protocol allocates one of three levels of ‘potential for positive mood’ to each BCC. The codes written in Table 18 those written in italics have moderate potential, those underlined have low potential, the remaining codes have high potential These groupings became important when following DCM ‘operational rules’ which are described below, and when completing the analysis which is described in Chapter 6.

A number of the codes are self-explanatory however for those that are not, examples are included illustrating how they were used, in Table 18.

Table 18: *Examples of Behaviour Category Codes allocated during the observations*

BCC	Allocated when *plwd…*
D	put on, or took off, the gloves and apron
E	sang (see Figure 7)
L	looked at magazines, and the activity instruction leaflet (see Figures 4 & 5)
O	spent some time smoothing their apron down (see Figure 6).
P	were supported by care home staff to put on, or take off, the gloves and apron
V	engaged in preparing the food

Once a BCC was allocated, a corresponding ME value was linked to it. The protocol for DCM8 lists 6 ME values ranging from -5 to +5 in intervals of 2, using odd numbers only. The full range of DCM ME values can be found at Appendix 4, however only 4 were observed by the researcher which are described in the Table 19.

Table 19: *ME values observed during the study according to DCM protocol*

Mood	ME value	Engagement
Very happy, cheerful. Very high positive mood	+5	Very absorbed, deeply engrossed/engaged
Content, happy, relaxed. considerable positive mood	+3	Concentrating but distractible. Considerable engagement
Neutral. Absence of overt signs of positive or negative mood.	+1	Alert and focused on surroundings. Brief or intermittent engagement
Small signs of negative mood	-1	Withdrawn and out of contact.

There are two dimensions to these values; mood and engagement. Mood can be observed by noting a person's facial expression, body language, posture, and content and tone of communication (University of Bradford, 2016, p.10). Engagement may be with another person, an activity or an object, and may include watching, touching and communication (University of Bradford, 2016, p.11). The operational rules followed to allocate an appropriate BCC and ME are described in detail in Appendix 28 with some examples of how the rules were operationalised in this thesis.

5.4.1.3 Focus Groups

Focus groups for participants were completed immediately after the final activity session (week 4) at the table where the activities had been completed. The researcher, the activities facilitator and care home staff were present to support *plwd*. Focus groups for care home staff were arranged for a suitable date as near to the completion of the intervention as was operationally possible for the care home. The RO staff focus group was completed at a quiet table in the dementia care unit the week following the intervention. The IG care staff focus group was completed in a private room two weeks after completion of the intervention. On these occasions only the care home staff and the researcher were present.

The researcher completed introductions, thanked the participants for attending, discussed some ‘ground rules’, advised participants of the limits of confidentiality and sought permission to record the interviews. The focus groups were then completed using a semi-structured approach based on the topic guides and recorded. Once the focus groups were completed the researcher thanked participants for attending one again and handed out debrief sheets

5.4.1.4 Weekly feedback sheets

These were handed out by the researcher or facilitator at the end of each session. The researcher or facilitator gave verbal instructions on how to complete them and supported residents living with dementia to complete them if they chose to, some participants chose not to. Care home staff also supported residents with dementia to complete the feedback sheets if they chose to do so, some participants chose not to.

5.4.1.5 Student questionnaires

Student questionnaires were completed pre- and post-intervention; during training sessions held for student participants in the university the week before the intervention, and at a debrief session held by the researcher after the intervention (see Chapter 4, section 5 for details of the data collection tool). Three of the ‘post intervention’ questionnaires were completed during the week in which the last intervention session was delivered, and one was completed in the following week due to illness. The researcher handed out informed consent forms followed by the paper-based questionnaire for completion, which were handed back by students on completion. The questionnaires were administered using exam like conditions; students were encouraged to complete them without speaking to obtain individual views. The strengths of this approach were that students were able to ask any questions of the researcher if they were unsure of anything, and data was gathered quickly. However, it is recognised having the interviewer present may have invoked some interviewer effects and students may also have felt some time pressures. Once all questionnaire data was gathered the following analyses were completed.

5.4.2 Data preparation and analysis

This section will outline the preparation and analysis that was completed on all data collected. Table 20 outlines the preparation and analyses that was completed on data gathered from each method used, which is described in the sections below.

Table 20: *Data preparation and analysis*

Data collection tool	Analysis
DCM	Individual participant data: Maps were produced showing the ME and BCC of 1 *plwd* per weekly session across three timepoints Amalgamated data/Group averages The total amount of time that *plwd* spent in each ME (ME-1, +1, +3, +5) was calculated. T-tests were completed to compare the amount of time that each group spent in ME+1 at TP2. The total amount of time that *plwd* spent in each of the 'top 3' BCC's (A, F, V) were calculated. T-tests were completed to compare group averages at TP2 The average ME values of *plwd* were compared between groups at TP2 and within the IG group across three timepoints (before, during and after each activity session).
Session Feedback sheets	Calculations were made of the number of responses received in each mood category (very unhappy, bit unhappy, ok, happy, very happy).
Questionnaires	T-tests were completed to compare pre/post scores on DAS Calculations were made of the number of negative, neutral, and positive words generated pre/post intervention. Simple comparisons were made between the length of the list and nature of the words on it.
Focus Groups	Thematic Analysis was used to identify key themes.

5.4.2.1 Dementia Care Mapping Data

Three types of data were recorded during the mapping process; observation notes, BCC, and ME values. The observation notes which provided context to the numerical BCC and ME data were typed up in 5-minute timeframes (see example at Appendix 25). The numerical BCC and ME data were entered into the computer package provided with DCM and 'maps' were produced which showed the mood and engagement of the participant and the behaviour that they engaged in across time; these maps are presented in Chapter 7. The data from all four maps for each intervention (RO and IG) was then amalgamated to produce group averages and draw some comparisons between groups and across time points.

5.4.2.2 Weekly session feedback sheets

The feedback sheets were amalgamated for each group. Calculations were made of the numbers of responses that were received in each category (very unhappy, unhappy, ok, happy, very happy). Comparisons were made between the groups.

5.4.2.3 Focus groups

Data preparation and analysis began within days of the focus groups using thematic analysis (TA), which is a method, of identifying and analysing patterns in qualitative data. Unlike other approaches to qualitative analysis TA does not come as a 'package', which is bound to theories, frameworks, and suggested style of questions. TA is flexible and the emphasis on choice of how to use it and underpinning theories rests with the researcher (Clarke et al., 2015).

I used TA in two ways, to answer two different research questions. The data that I had gathered during the participant focus groups referred to research question one and therefore was based on their own experience. However, the data that I had gathered during focus groups with care home staff had two areas of focus; I asked about their opinions and observations of the participants, and what they felt about the practicality of the intervention for the care home setting. Therefore, I used a basic adaptation of template analysis for the data which addressed Question one, and the six-step method of Thematic Analysis advocated by Braun and Clarke (2006) for data which addressed question two

Template analysis is a style of thematic analysis that enables the use of a priori themes. This approach to thematic analysis is clear, structured, and flexible (Brooks et al., 2015). It is particularly useful for building on existing theory, and capturing theoretical concepts that have informed the design of a study (Brooks et al., 2015) therefore fits the aims of this study. A limitation of template analysis is that the focus is on cross cases which may result in the loss of some holistic data on an individual basis (Brooks et al., 2015), however in this study this was not an issue as the research was exploring the experience of the group during the intervention, and the sample size was small which meant that individual experiences were visible.

I completed the first two steps of the six-stage process of analysing TA recommended by Braun and Clarke (2006) for all data; familiarisation with the data and noting items of interest, coding, searching for themes, reviewing themes, defining and naming themes and writing the report. I first familiarised myself with the data by listening to the focus group audio recordings from start to finish, three times and made notes of 'observations and insights' (Clarke et al., 2015, p.232) by hand. The next step involved data preparation and transcribing, which I completed within days of the focus groups. I made every effort to ensure that the transcription was an accurate reproduction of the contents of the focus groups. To achieve this, I noted what was said and by whom, plus any mumbles and utterances, without changing them. Notations were also made of laughter, coughs and any other noises as I considered them particularly important for *plwd* as forms of verbal communication which may be challenging for *plwd,* therefore I wanted to capture everything. Focus groups are uniquely positioned to 'uncover the unique experintial data that determinse the complexity of social situations' (Massey, 2011, p.25) therefore the data included interesting details regarding interactions between participants and the context which are a key aspect of focus groups (Ansay et al., 2004, Barbour, 2013).

The transcriptions were prepared on Microsoft Word documents with three columns: one column for entering the transcribed data, the second column for comments/ codes, the third column for notes relating to the context. (See Appendix 32) for an example. I did not use NVivo as the data set was small and I wanted to stay 'near it' (Patton, 2015).

I started the coding process by proofreading the material and adding comments. However, this is where I treated the two data sets differently according to the question that it addressed. With the first research question in mind , *whether the intervention had the potential to improve wellbeing amongst plwd*, I developed a template based on Kitwood's theories which are described in Chapter 3. I initially coded the data looking for examples of wellbeing or illbeing according to Kitwood (1997b), and then designed the data template which I used to link examples of wellbeing/illbeing to each of the five psychological needs; attachment, occupation, inclusion, identity and comfort. An extract of the template is presented in Table 21, with an example relating to attachment.

Table 21: *Coding template for research question one*

A priori theme	*Description*
	Attachment
Need for	*Ppt 17: …can be quite competitive can't they for attention*
Need met	*Ppt 8: all the little between everybody little chitty chats going on*
Wellbeing associated	*Ppt 12: it's been nice meeting different people*
Illbeing associated	*Ppt 8: They've all said they are going to miss you*

There was some data produced by *plwd* that did not answer the reasearch question therefore was not coded. Each data item was coded fully before moving on to the next; the transcripts from the RO focus groups were coded first and followed by the transcripts from the IG groups. As this was a small data set I applied the initial template to the full set of data without modification, which may be necessary in a larger data set (Brooks et al., 2015). Once all data was coded all instances of the codes were collated.

The data from care staff transcripts that did not address this question, was put to one side at this point and was coded later. I coded this data with the research question in mind and added codes (words or brief phrases) to the transcription that captured the essence of the data (Braun & Clarke, 2013, p.205). I used the final four steps identified by Braun and Clarke (2006) to do this; coding, searching for themes, reviewing themes, defining and naming themes and writing the report.

5.4.2.4 Student questionnaires

DAS scale: data gathered from the DAS scale was entered into IBM SPSS version 23, which was used to complete the analyses. The data was checked for outliers and none were found. The negatively worded items on the scale were reversed and total scores were calculated for the total of the scale and the two sub-scales (knowledge and comfort). A paired samples t-test was used to determine whether there was a statistically significant difference (Pallant, 2016). The results relating to statistical significance and effect size is presented in Chapter 8 alongside the raw data as suggested by Dankel et al. (2017). A paired samples t-test was identified as appropriate as the aim of the analysis was to compare the students' scores across two time points (pre and post intervention). The paired samples t-test does this (Pallant, 2016).

There is some debate as to the suitability of the t-test for small data samples such as the four students involved in this study. Siegel (1957, p.18 cited in de Winter, 2013, p.2), for example, stated that 'if samples as small as 6 are used, there is no alternative to using a non-parametric statistical test unless the nature of the population distribution is known exactly'. However, Janušonis (2009) recommended the use of the t-test for samples of 3 or 4 and states that the 'Wilcoxon Signed Rank Test should never be used if one group has 3 cases and the other has 3 or 4 cases' which is the situation in the current study as one participant did not answer one of the questions (Q7) at time point 1 which meant that her results were omitted from calculations relating to the knowledge scale and the overall DAS scale. This meant that there are 3 cases in one group (pre intervention) and four cases in the other (post intervention), therefore the use of the Wilcoxon Signed Rank Test (the non- parametric alternative to the t-test) is under question for my analysis.

However, de Winter (2013) argues that t-tests are credible in very small samples if a strong effect is predicted, the literature review that was conducted for this study led me to believe that this would be the case. Four IG studies which used the DAS scale (Garrie et al., 2016; George et al., 2013; Roberts & Noble 2015; Lokon et al., 2017) found an increase in DAS scores. Roberts and Noble (2015) reported an improvement in overall DAS scores, Lokon et al. (2017) found an increase on both subscales (comfort and knowledge) and 19 out of the 20 items, George et al. (2013) found an increase in knowledge and comfort) and 12 of the 20 items, Garrie et al. (2016) also found an improvement in overall DAS score and 10 of the 20 items; all improvements reached statistical significance. Only one of these articles (Lokon et al., 2017) discussed effect size and found a large effect size in the overall DAS score and 5 items (2,4,5,7 & 12). On the basis of these results and the fact that the researcher could see with her naked eye what appears to be a large effect the researcher for the current project predicted a strong effect and therefore made the decision to used t-tests for the analysis.

Researchers suggest that effect size is also reported alongside statistical significance in all published articles now (Tomczak & Tomczak, 2014; Schober et al., 2018). In fact, Sullivan and Feinn (2012, p.279) suggest that 'the effect size is the main finding of a quantitative study'. The test of significance = size of effect x size of study (Kramer & Rosenthal, 1999, p.60) therefore as the size of the study increases, so do the chances of results reaching significance, however to conclude that a non-significant result means no effect is incorrect. In studies using very small samples it is uncommon for results to reach statistical significance however the effect size ('also known as the strength of association') (Pallant, 2016, p.212) needs to be considered in such situations. Field (2018, p.113) states that; 'An effect size is an objective and (usually) standardised measure of the magnitude of observed effect' (Field, 2018, p.113). Calculating the effect size is particularly useful in studies using small samples, and when assessing an intervention such as this one.

Kramer and Rosenthal (1999) suggest that effect size is a better indicator of the significance of a result than the traditional test of significance, in small samples. Coe (2002, p.7) agrees, and argues that although 'it is important to know the statistical significance of a result, since without it there is a danger of drawing firm conclusions from studies where the sample is too small to justify confidence' (as in the current sample). He continues by stating that 'statistical significance does not tell you the most important thing; the size of the effect'. This is what the current study aims to assess, the effect size of any change reported in students' comfort and knowledge with dementia. Field (2018) also agrees. Coe (2002) however makes the point that the reliability of measures must be known when assessing effect size. The reliability and validity of the DAS scale have been measured in student populations previously, (which were reported in Chapter 5). Although there are a number of effect size calculations Cohen’s d is popular and generally used within the social sciences literature (Peeters, 2016) therefore was adopted for the current study. Cohen’s d was calculated using Social Science statistical website (Social Science Statistics, n.d.).

There are however some limitations to using the effect size. Schober et al., (2018, p.1068) highlight the fact that effect size ‘does not imply or require causality and the reported effect size provides no information on whether there is actually a direct effect of 1 variable on another’. They suggest that researchers ‘interpret research results carefully, rather than reviewing them as conclusive evidence’ (Schober et al., 2018, p.1071). Dankel et al. (2017) suggest that ‘the effect size calculation should be a supplementary statistic and should be reported in addition to the raw data’ (p.447) as this will show how the intervention has potentially impacted each participant as opposed to measuring the size of chance between pooled average data (from all 4 participants. This has therefore been reported in the results section.

The Phenomenological Word Task (discussed in Chapter 5): the words generated from all 4 questionnaires were amalgamated and the percentage of positive, negative, and neutral words were calculated pre- and post-intervention to assess change.

How the data was triangulated

Observational data gathered by the researcher using DCM was triangulated with data gathered from care home staff using focus groups and self-report data gathered from feedback sheets and focus groups, to answer research question one (see Table 22). This enabled the researcher to ‘seek convergence, corroboration, correspondence of results from the different methods’, and types of data (Greene et al., 1989, p.147). Self-report data collected from participants was compared with observational data to explore whether this data was convergent or divergent. Qualitative and quantitative data was used in a complementary way to explain the outcomes and processes.

Table 22*: How data was integrated to answer the research questions*

Question	Participants	Data collection methods
Does the intervention have the potential to enhance the wellbeing of *plwd*	*plwd*	Observation (DCM)
	All participants	Self-report: Weekly session feedback sheets
	care staff	Focus groups

The DCM data was explored in the same way as the qualitative data; I initially looked for overall levels of wellbeing or illbeing then linked examples to the needs. I added the data into the template that I previously designed for the qualitative analysis. Table 23 provides an example based on attachment.

Table 23: *Coding framework used in the qualitative analysis*

A priori theme	*Description*
Attachment	
Need for	RO carer focus group: *Ppt 17: …can be quite competitive can't they for attention*
Need met	RO carer focus group: *Ppt 8*: *all the little between everybody little chitty chats going on* DCM: A: Interacting was the behaviour that *plwd* engaged in the most
Wellbeing associated	*IG participant carer group: Ppt 12: it's been nice meeting different people* DCM: Ppt 9 experienced their highest ME (+3) when interacting with students
Illbeing associated	*RO carer group: Ppt 8: They've all said they are going to miss you*

5.5 CHAPTER SUMMARY

This chapter outlined the complexity of the preparation process which enabled the intervention to be implemented smoothly into two care homes in Wales. Detailed plans were developed for the activities, the scheduling of the sessions, and the implementation process. Collaborations were formed with care home staff and details of the intervention were agreed with all parties. The intervention protocol was followed, with some minor exceptions, and 14 participants engaged in the intervention: seven *plwd*, three residents, and four students. The next chapter three chapters will present the findings of the study from the perspectives of residents, staff and students.

6 CHAPTER 6: PRESENTATION AND DISCUSSION OF DCM FINDINGS

6.1 INTRODUCTION

The purpose of this chapter is to address the research question: *Does the proposed intervention have the potential to enhance the wellbeing of plwd*?

The chapter presents the analyses of DCM data. The first section provides an illustration of the individual experiences of *plwd* that were mapped during the study. Eight individual maps were completed during the interventions which are presented alongside short narratives which contextualise the observations. The maps illustrate the mood and engagement that *plwd* experienced, and the behaviours that they engaged in. The second section presents findings based on the experimental framework, to assess any findings which are unique to the IG intervention. In this section comparisons are drawn between the experiences of the RO and IG groups during the activity sessions, and changes in the mood and engagement of *plwd* in the IG group across time.

6.2 DCM COMPLETED DURING THE STUDY

Eleven hours and 30 minutes of DCM mapping was completed (138 Timeframes) during the whole study. Thirty-one Timeframes were observed during TP1, 84 during TP2, and 23 during TP3. Eight individual maps were completed according to the DCM protocol described in Chapter 6. Each map represents the mood and engagement experienced by one *plwd* during the observation, and the behaviours that they engaged in. All maps produced in this thesis are presented in the same way; ME values are indicated on the vertical axis of the maps, and BCC's are indicated on the horizontal axis. Each point on the map indicates the BCC that the *plwd* was predominately engaged in, and the predominant ME value that the *plwd* experienced during the 5-minute timeframe. Mapping completed at TP1 and TP3 is represented with a dotted line, mapping completed at TP2 is represented by a continuous black line. For clarity, each whole map will be described as the observation, the continuous line (TP2) will be described as the activity session. Gaps in the maps indicate times where mapping data was not entered, generally because the *plwd* was sleeping, or had left the room.

The maps are presented with a short narrative which; provides some context to the observation, discusses briefly what is illustrated, and outlines the conclusions drawn from the observation.

6.2.1 Maps completed during the RO intervention

Four maps were completed during the RO intervention. All *plwd* were mapped in rotation. As all *plwd* were mapped during the first three weeks, the rotation began again at week 4 which meant that ppt 1 was mapped a second time.

6.2.1.1 Week One

The first activity session was attended by two *plwd*, therefore, two care staff engaged in the activity session providing a 1:1 experience for the *plwd* who attended. Ppt 1 was mapped. As it was the first session the care staff and activities facilitator were a little unfamiliar with their role, and I became engaged in the preparation and clearing up, therefore, no mapping was completed before or after the activity session.

As can be seen in Figure 4 the *plwd* left the room for a short while, and spent all of the time that they were mapped in positive ME, with 77.8% of this in ME+1, and 22.2% in ME+1. The *plwd* spent most time (33.3%) eating and drinking (F), preparing the ice-cream (V) and looking at the reminiscence materials (L) when they appeared happy and relaxed. They spent least time (11.1%) reminiscing (B) and being supported to put the gloves and apron on for the activities (P); during this time, they appeared alert with a neutral facial expression.

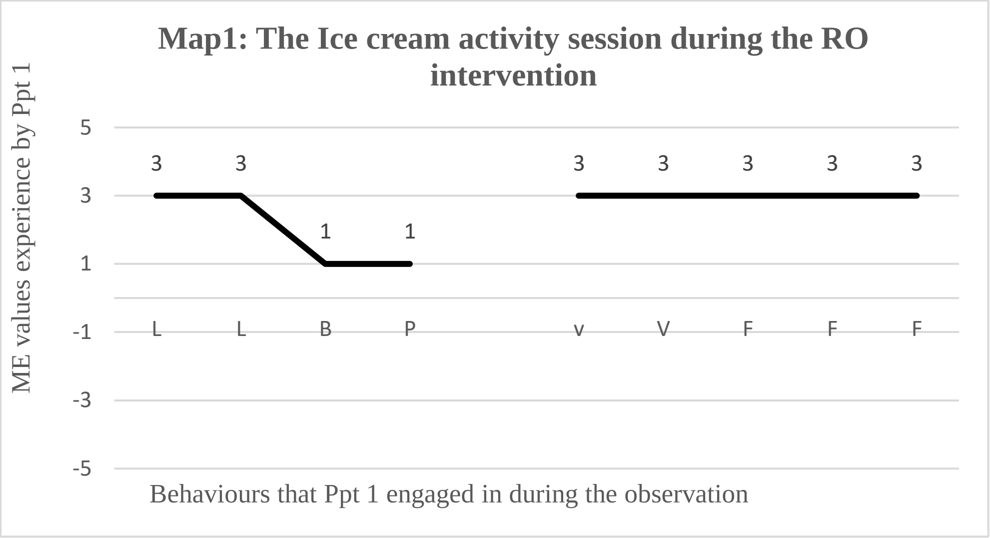

Figure 4: *Mapping completed during week 1 of the RO intervention*

In summary the *plwd* spent most of the observation engaged in preparing and sharing food and experienced relative wellbeing during the session.

6.2.1.2 Week Two

The second session, which involved indoor gardening was attended by five participants; two *plwd* and three residents. The *plwd* were already sat together at the table when the residents arrived from other areas of the home, therefore the residents sat together in the empty seats. This meant that the planned 1:1 element of the intervention was not followed, however, all participants were well supported by two care home staff and the activities facilitator. Ppt 2 was mapped. The mapping completed before the activity session was a little short as Ppt 2 was in the garden when I arrived; DCM mapping was only completed in the communal room where the activities were completed throughout this study. Before the activities started a member of care staff advised me that the *plwd* were tired as they had been out, therefore myself and the activity facilitator were mindful of this and kept the activity session short.

As Figure 5 illustrates the *plwd* spent most of their time (94.7%) in positive Mood/Engagement; 63.1% in ME +1, 26.3% in ME+3, and 5.2% in ME+5. The Ppt spent all of their time during TP1 and TP3 in either ME+1 or ME+3; during the activity session they experienced a wider range of ME values which included short periods of time in ME-1 as they put on the gloves and apron for the activities and ME+5 when they appeared very absorbed in the indoor gardening. The Ppt spent most of their time (26.3%) indoor gardening (V*)* which they consistently engaged in for five timeframes. They interacted (A) across all three timepoints which accounted for 21% of the total observation, looked at magazines (L) for most of TP1, and ate and drank (F) for most of TP3. The least amount of time (5.3%) was spent reminiscing (G) and putting put the gloves and apron on in preparation for the activities (P).

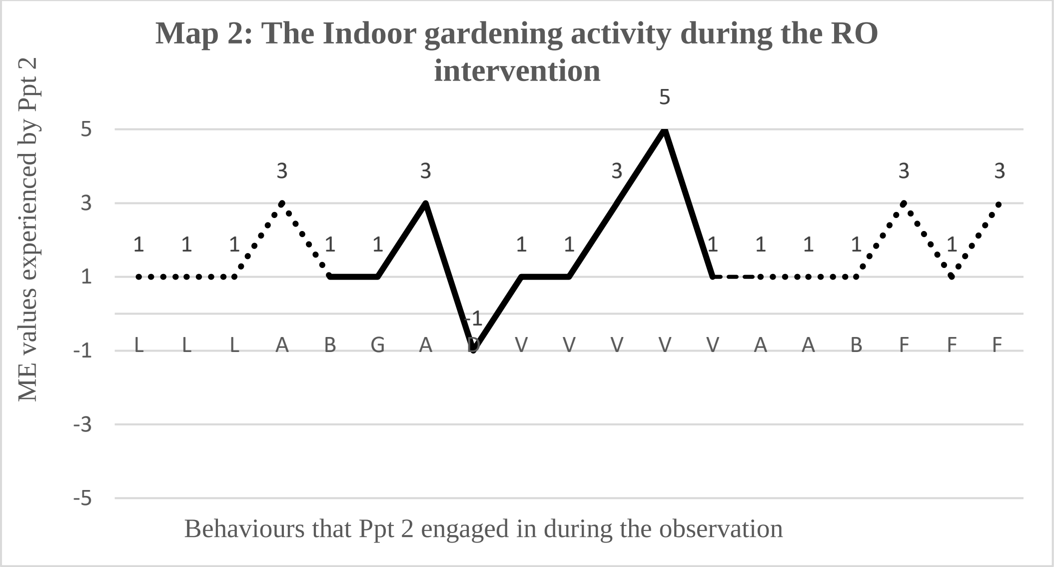

Figure 5: *Mapping completed during week 2 of the RO intervention*

In sum, Participant 2 appeared to enjoy this session. Whilst preparing for the activity had a brief, negative effect on their wellbeing, the indoor gardening had a positive effect. The mood and engagement of the participant increased while they were engaged in the gardening, reaching ME+5 at one point, the highest ME in the DCM protocol.

6.2.1.3 Week Three

The third session started with three participants (two *plwd* and one resident). A third *plwd* was sleeping when the session started but joined in half way through, when they woke. As only 1 resident attended the activity session the planned 1:1 element of the intervention was not followed, however, the *plwd* were well supported by two care home staff and the facilitator. The participants were all sat at the table some time before the activities were due to start; therefore, we started early which meant that the 'pre-activity' mapping was a little short. Ppt 3 was mapped.

As can be seen in Figure 6 the Ppt spent all of their time in positive Mood/Engagement; 85.7% in ME+1, 14.3% in ME+3. The behaviour category code (BCC) that the ppt engaged in the most was eating and drinking (F), which accounted for 42.8% of their time, and was observed across all three timepoints. Interacting with others (A) was only observed during TP2, but this accounted for 33.3% of the total observation, and most of the time that they appeared happy and engaged. The least amount of time (4.8%) was spent; taking their apron off (D), looking at reminiscence materials (L), and smoothing down their apron (O).

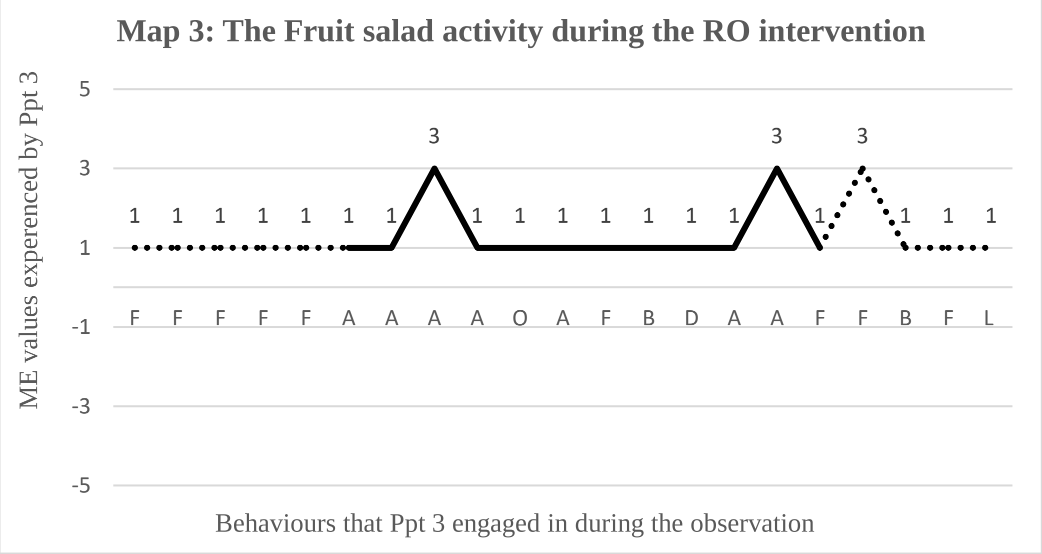

Figure 6: *Mapping completed during week 3 of the RO intervention*

In sum, the intervention appeared to enhance the wellbeing of Participant 3 as they experienced most of the higher ME (+3) during TP2. The Ppt engaged with it the activities by watching, eating the fruit, and talking; they particularly enjoyed interacting with others.

6.2.1.4 Week Four

The fourth and final activity session of the RO intervention was attended by three participants (two *plwd* and one resident). As only 1 resident attended the session the planned 1:1 element of the intervention was not followed, however, the *plwd* were well supported by two care home staff and the facilitator. Ppt 1 was mapped for the second time.

As can be seen in Figure 7 the participant fell into a light sleep for some time (15.8%) towards the end of TP1, and woke as the activities started. According to DCM protocol no ME values were recorded during the time that they slept. Ppt 1 spent all of the time that they were awake in positive Mood/Engagement; 68.7% in ME+1, and 31.3% in ME+3. The Ppt spent the whole of the activity session in ME+1, while they walked around (K), were supported to put gloves and an apron on for the activities (P), and helped prepare sandwiches (V). They appeared happier and more engaged (ME+3) as they sang during TP1, and ate and drank during TP3.

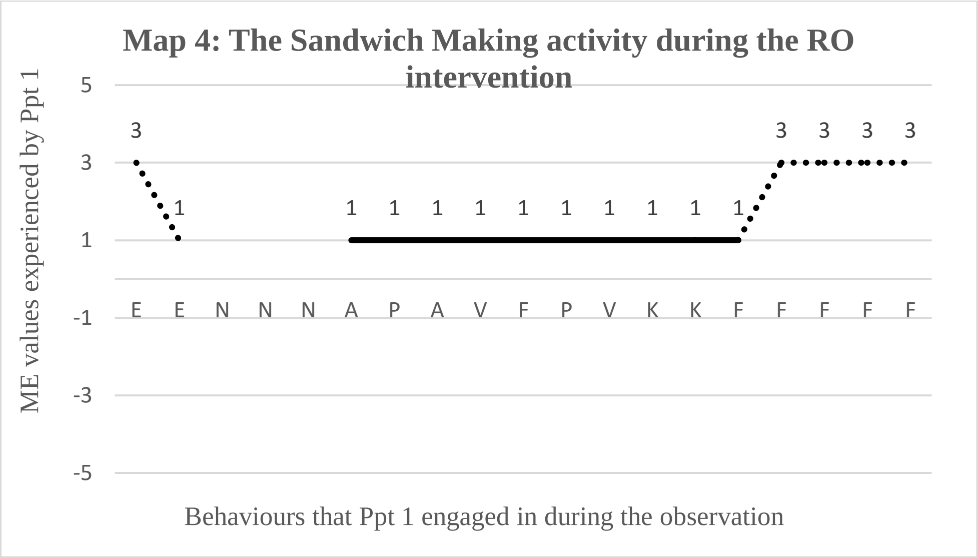

Figure 7: *Mapping completed during week 4 of the RO intervention*

In sum, although the Ppt appeared to experience relative wellbeing throughout the observation they appeared more relaxed and engaged before and after the activity session. They engaged with the activities for short periods but generally appeared too tired to engage with the organised activities.

6.2.2 Maps completed during the IG intervention

Four maps were completed during the RO intervention. All *plwd* were mapped in rotation. As all *plwd* were mapped during the first three weeks, the rotation began again at week 4 which meant that ppt 9 was mapped a second time.

6.2.2.1 Week One

The first activity session was attended by all 8 participants; four students and four *plwd*. Ppt 9 was mapped. The mapping at TP1 was particularly short as the care home manager provided an induction for students which I attended.

As shown in Figure 8 the participant spent all of their time during the observation in positive ME; 84.2% in ME+1, 15.8% in ME+3. All of the higher ME values were experienced during the activity session, as the *plwd* interacted with others, and engaged with the ice-cream making. Most of their time (47.4%) was spent interacting, all of which was completed during TP2. This was followed by 21% of the time watching, which was all completed during TP1 (1TF) and TP3 (3TFs). Ten and a half percent of their time was spent eating and drinking, all during the activity session. Low amounts of time (5.3%) were spent; engaging in the activities (V) walking to the activity table (K) being supported to put on the apron and gloves ready for the activities (P), preparing the ice-cream (V), and taking the gloves and apron off at the end.

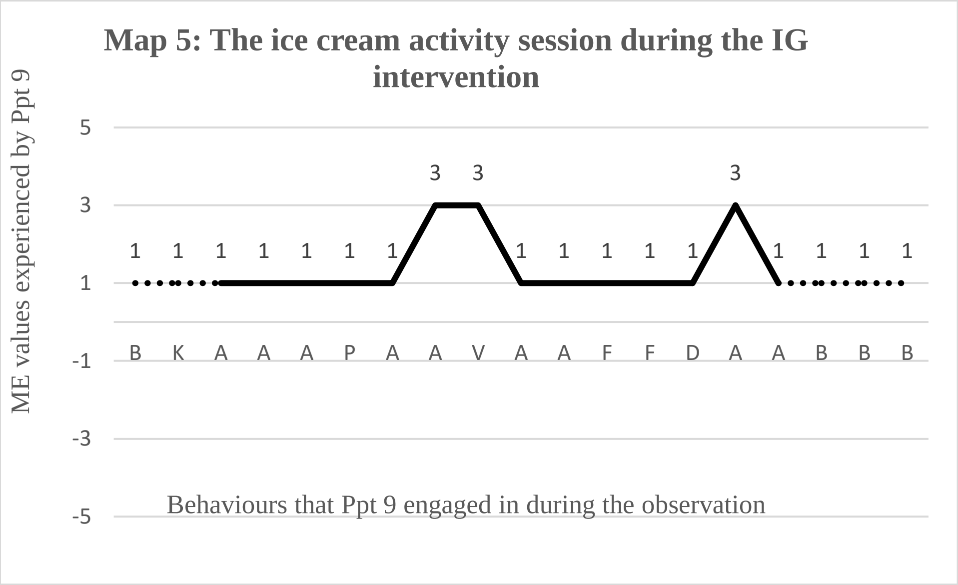

Figure 8: *Mapping completed during week 1 of the IG intervention*

In sum, the intervention appeared to enhance the wellbeing of Participant 9. The *plwd* appeared to experience relative wellbeing during the whole observation, with the highest experienced during the activity session.

6.2.2.2 Week Two

All eight participants attended the second session; four students and four *plwd*. Ppt 10 was mapped. As can be seen in Figure 9 Ppt 10 spent most of their time (94.7%) in positive ME; 63.2% in ME+1, 31.6% in ME+3. All of the experiences in the higher ME values were experienced during TP2; most (5TF) were related to interacting, (1TF) to eating and drinking (F). The lower value (ME-1) was also experienced during TP2 when the Ppt appeared put on the gloves and apron for the activities. The participant engaged in four behaviours during the observation, spending most of their time (63.1%) interacting with others, less time eating and drinking (15.8%), and equal amounts of time (10.5%) putting their gloves on for the activities, and walking around (K). Interacting with others was the only BCC that the *plwd* engaged in across all three timepoints.

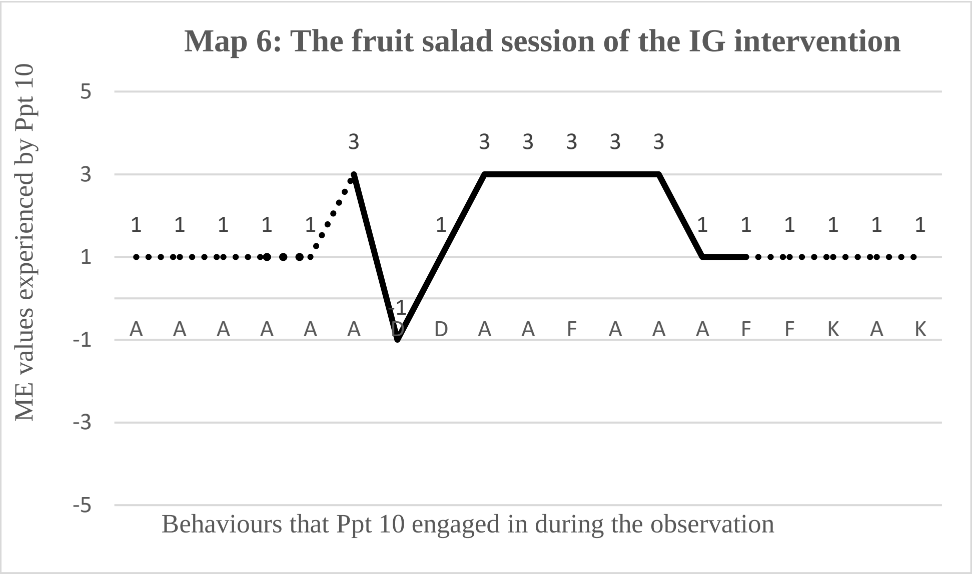

Figure 9: *Mapping completed during week 2 of the IG intervention*

In sum, the intervention appeared to enhance the wellbeing of Participant 10; apart from a short period when they were putting the gloves and apron on, they appeared happy and engaged during the activity session. This compared favourably to the observations completed before and after the activity session, when they remained alert with a neutral facial expression.

6.2.2.3 Week Three

Seven participants attended the start of the third activity session; all four students and three *plwd*. However, one *plwd* felt unwell and left part way through the activity session leaving a ratio of 2 students to each *plwd*. Ppt 12 was mapped. The mapping at TP3 was short as the *plwd* left the communal room to go for a lie down.

As seen in Figure 10 the participant spent all of their time in positive ME; 37.5% in ME+5, 31.25% in ME+1 and 31.25% in ME+3. The *plwd* spent all of TP 1 in ME+1, and became increasingly happier and more engaged during TP2, which continued through TP3. The Ppt spent most of their time (68.7%) during the whole observation interacting with others (A), which was the only BCC that they engaged in across all Timepoints, and was the BCC that they experienced as most enjoyable. The *plwd* appeared very happy and engrossed (+5) during six timeframes of the observation, five of which were associated with interacting with others, one was associated with indoor gardening. The ppt spent 12.5% of their time indoor gardening (V), and small amounts of time (6.2%) watching (B), putting the gloves and apron on (D), and reminiscing (G).

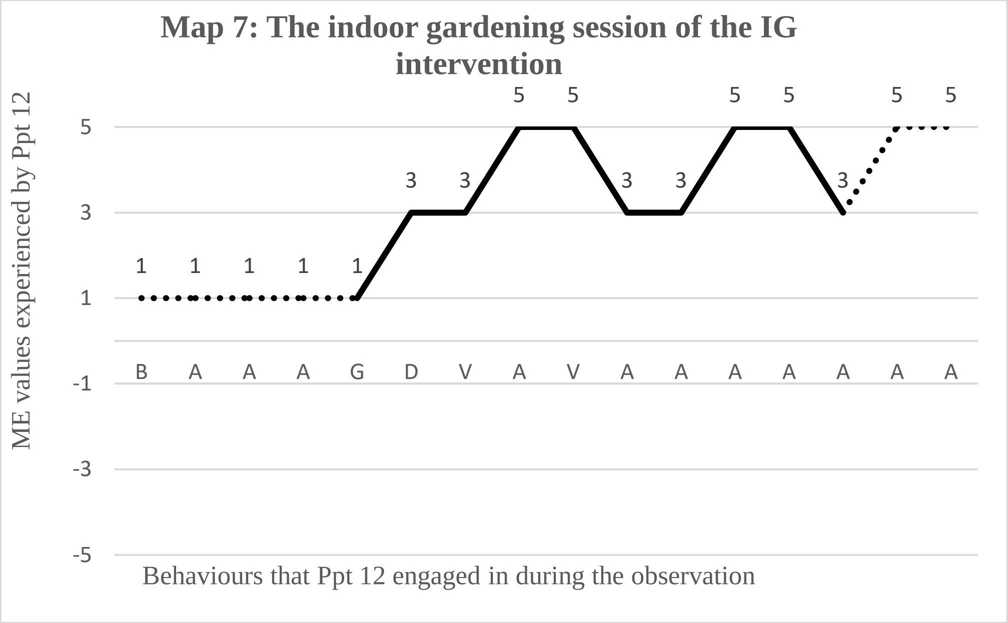

Figure 10: *Mapping completed during week 3 of the IG intervention*

In sum, the intervention appeared to enhance the wellbeing of participant 12, who clearly enjoyed interacting with others and indoor gardening; this illustrates the added value of introducing students.

6.2.2.4 Week Four

Six participants attended the fourth activity session; three students and three *plwd.* Ppt 9 was mapped for the second time. No mapping was completed after the activity session as the participants engaged in the focus group.

As can be seen in figure 11 the participant spent most of the observation (93.7%) in positive ME; 81.2% in ME+1, 12.5% in ME+3. The participant showed small signs of discomfort (ME-1); for a short period (6.25% of the time) while they were being supported to take their apron and gloves off. Most of the observation (43.7%) was spent watching, followed by eating and drinking (37.5%), interacting (12.5%) and being supported to put on the gloves and apron (6.2%). The *plwd* experienced the highest ME values when they were watching (B) around the start of the activity session and the students arrived.

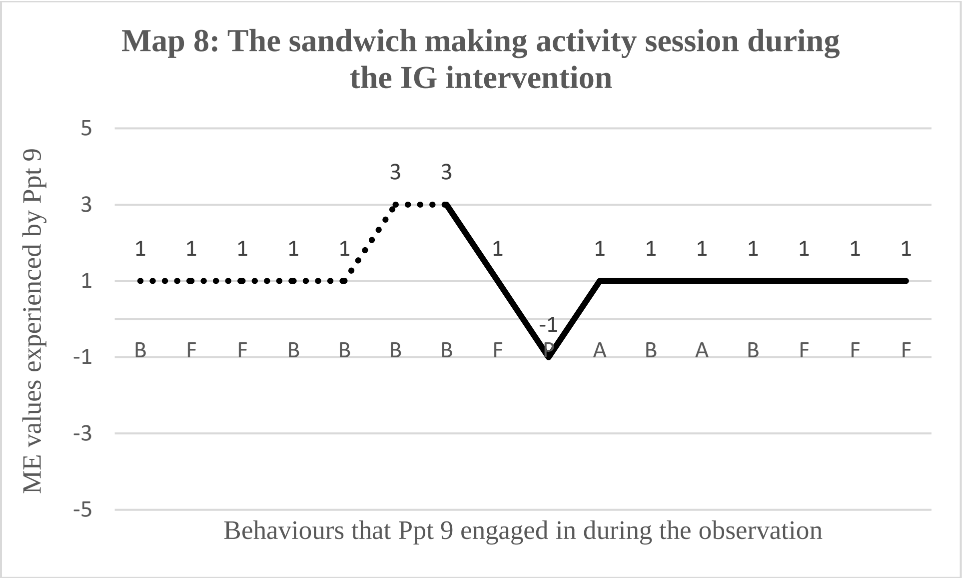

Figure 11: *Mapping completed during week 4 of the IG intervention*

In sum, based on the DCM scores, the intervention showed limited potential to enhance the wellbeing of the participant, and there were signs of discomfort (-1); this notwithstanding, opportunities to engage with students positively affected their level of happiness and engagement (+3), and suggests the added value of having introduced the intergenerational element to the activity.

6.2.3 Conclusions based on the Individual Maps

For the most part the intervention showed potential to enhance the wellbeing of *plwd* however there were some aspects of it that appeared to negatively impact their wellbeing albeit for brief periods, during week 2 of both interventions. This was predominately when participants put the gloves and apron on for the activities, regardless of whether they did this themselves or were supported to do. Engagement appeared highest during the indoor gardening activity sessions, and lowest during the sandwich making.

6.3 FINDINGS FROM THE EXPERIMENTAL FRAMEWORK

A quasi-experimental pre-test post-test design with a non-equivalent control group was used to explore differences in how the groups experienced and engaged in the activity sessions. and differences in the ME of the IG group across time.

6.3.1 Comparisons between the groups during the activity sessions

This section focuses on TP2 to explore differences in the way that the groups experienced, and engaged in, the activity sessions. Differences were found in the length of the activity sessions, the ME experienced by *plwd*, and the BCC that *plwd* engaged in.

Although each activity session was designed and planned to last approximately an hour, in practice the session length was dictated by contextual factors such as the group size and the amount of time that was spent supporting participants. Sessions were delivered at a pace that was comfortable for the participants. As illustrated in Table 24, more mapping was completed during the IG intervention; 44 timeframes were completed compared to 40 during the RO intervention.

Table 24: *The amount of mapping completed during each intervention*

Activity	**RO Intervention**		**IG Intervention**	
	Time	TF	Time	TF
Ice cream	45 minutes	9	1hr 10mins	14
Fruit salad	1hr	12	50mins	10
Indoor Gardening	45mins	9	50mins	10
Sandwich Making	50 mins	10	50mins	10
Total	3hrs 20 mins	40	3hrs 40 mins	44

Calculations were performed to assess the number of Timeframes that *plwd* spent in each ME value, which found differences between the groups. The RO group spent more time than the IG group in positive ME values overall; 97.5%, compared to 95.5%. However, the RO group spent a larger proportion of that time in ME+1 compared to the IG group, which spent more time in the higher ME values.

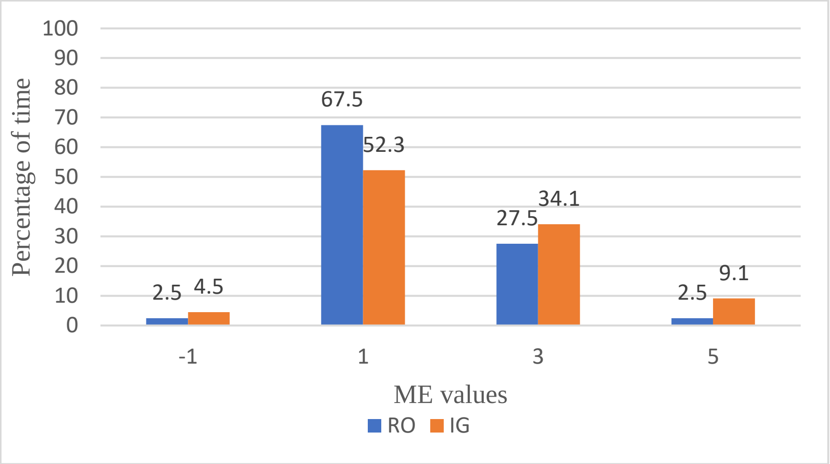

Figure 12: *Distribution of Mood and Engagement Values Across the Activity Sessions*

An independent samples t-test was conducted to compare the percentage of time spent in ME+1 scores for the RO and IG groups. There was no significant difference the percentage of time for RO (M =65.27, SD = 34.05) and IG (M = 49.65, SD = 35.20); t (6) = 0.64, p = .55. The magnitude of the difference in the means was 0.45 which represents a small effect size according to Cohen's d.

Differences in the distribution of ME values resulted in a higher average ME for the IG group. An independent samples t-test was conducted to compare the average ME for the RO group and IG group. There was no significant difference in average ME for RO (M =1.63, SD =0.66) and IG (M =1.95, SD=1.20); t (6) = -0.47, p =. 66. The magnitude of the difference in the means was 0.33, which represents a small effect size according to Cohen's d.

Calculations were performed to assess the number of Timeframes that *plwd* spent engaged in each BCC. Ten behaviours in total were observed during the activity sessions, which are shown in Figure 13. Nine of the BCC's were high potential categories which both groups spent most of their time engaged in, 93.25% in the IG group compared to 92.5% in the RO group. There were five behaviours that both groups engaged in: interacting (A), eating and drinking (F), preparing food (V), putting the gloves and apron on for the activities (D) and watching (B). The time that *plwd* engaged in each activity differed between the groups, however the most notable differences were experienced around interacting, and preparing the food. Both groups spent more time interacting than any other activity, however, the amount of time was much higher in the IG group; 52.3% compared to 25% in the RO group. The RO group spent almost three times as much time preparing the food as the IG group; 22.5% compared to 6.8%. In essence, the focus of the groups differed; the RO group focused more on the activities while the IG group focused more on interacting.

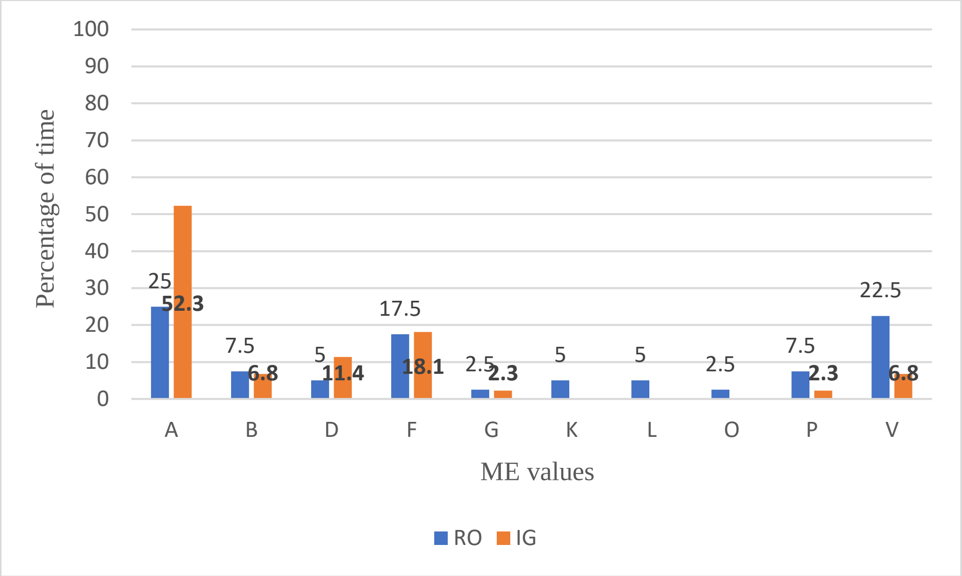

Figure 13: Distribution of Behaviour Category Codes Across the Activity Sessions

The three most common BCC's (A, F, and V), were highly collaborated with the research aims; (to provide meaningful activity based on preparing and sharing food, and a social connection with the outside world) therefore were selected for analysis. An independent samples t-test was conducted to compare the percentage of time spent in **A** for the RO and IG groups. There was no significant difference in the percentage of time for RO (M = 29.80, SD = 25.07) and IG (M =5 1.07, SD = 20.81); t (5) = -1.23, p =.27. The magnitude of the difference in the means was 0.923 which represents a large effect size according to Cohen's d. An independent samples t-test was conducted to compare the percentage of time spent in **F** scores for the RO and IG groups. There was no significant difference in the percentage of time for RO (M =23.33, SD = 8.79) and IG (M = 24.77, SD = 13.4); t (4) = -.15, p = .88. The magnitude of the difference in the means was 0.127 which does not reach even a small effect according to Cohen's d. An independent samples t-test was conducted to compare the percentage of time spent in **V** for the RO and IG groups. There was no significant difference in the percentage of time for RO (M =32.60, SD = 19.94) and IG (M = 13.55, SD = 9.12); t (3) = 1.21, p =.310. The magnitude of the difference in the means was 1.23 which represents a large effect size according to Cohen's d.

In summary, DCM data indicated that the IG group experienced higher mood during the activity sessions, and focused more on interacting whilst the RO group focused more on preparing the food. None of these differences were statistically significant.

6.3.2 Changes in the Mood and Engagement of the Intergenerational group across timepoints

One of the aims of the methodology was to calculate the average ME values of *plwd* and compare between groups, and across time however insufficient data was collected during the RO intervention to complete the analyses according to DCM protocol. The protocol states that 48 TFs are required to calculate average ME values when assessing the quality-of-care provision in care homes. A number of published intervention studies have been completed with less data than recommended (Crook et al., 2016; Hsu et al., 2015; Kontos et al., 2016). As shown in Table 25 the data gathered for each group during the activity sessions was just short of 48 Timeframes therefore meaningful comparisons could be drawn. The number of Timeframes observed during TP1 and TP3 was lower therefore analyses of this data was impractical.

Table 25: *The number of 5-minute timeframes observed during the whole study*

	TP1	TP2	TP3
	Number of Timeframes		
RO Intervention	14 *	40	14
IG Intervention	17	44	9
Totals	31	84	23

*Note: *11 timeframes were allocated values according to DCM protocol*

After completing the RO intervention, I made the decision to complete the mapping during the IG intervention using 1-minute Timeframes to gather sufficient data to complete the analyses, according to DCM protocol. Previous researchers have used Timeframes of differing length, including 1-minute Timeframes (Cooke & Chaudhury, 2012; Thornton et al., 2004).; I spoke to the Head DCM trainer at the University of Bradford about adopting this approach and they did not foresee an issue. The findings are illustrated in Figure 15. Maps were prepared of the 1-minute observations, which can be found at Appendix 35.

Data from all four maps was amalgamated; and calculations were performed to assess the number of Timeframes that the *plwd* experienced in each ME value across all timepoints. There was insufficient data to conduct statistical tests on all ME values across all timepoints therefore I focused the analyses on ME+1 as this was the most commonly experienced value. I completed t-tests to assess and changes between TP1 and TP2 as I wanted to compare the impact of the intervention from baseline.

A paired samples t-test was conducted to evaluate the impact of the intervention on the amount of time spent in ME+1. There was no statistically significant increase from TP1 (M = 89.3, SD =17.76) to TP2 (M = 61.57, SD = 22.31), t (3) = 1.84, p. › 0.16. The mean increase was 27.77 with a 95% confidence interval ranging from 20.24 to 75.79. The magnitude of the difference in the means was 0.92 which represents a large effect size according to Cohen’s d.

Average ME values for the group at each of the three timepoints were also calculated. The average ME was lower during TP2 using 1-minute timeframes, than reported using 5-min timeframes. This finding supports the view of previous researchers that 5-minute timeframes under represent negative experiences (Cooke & Chaudhury, 2012; Thornton et al., 2004), which are discussed in Chapter 4, section 5. As illustrated in Figure 14 change was found between average ME values of the IG group at TP1 and TP2, no change was found between TP2 and TP3. A paired samples t-test was conducted to evaluate the impact of the intervention on average wellbeing scores. There was no statistically significant increase from TP1 (M = 1.05, SD = .17) to TP2 (M =1.55, SD= .89), t (4) = -1.39, p › 0.26. The magnitude of the difference in the means was 0.70 which represents a medium effect size according to Cohen’s d. The mean increase was 5.00 with a 95% confidence interval ranging from 2.63 to 15.36.

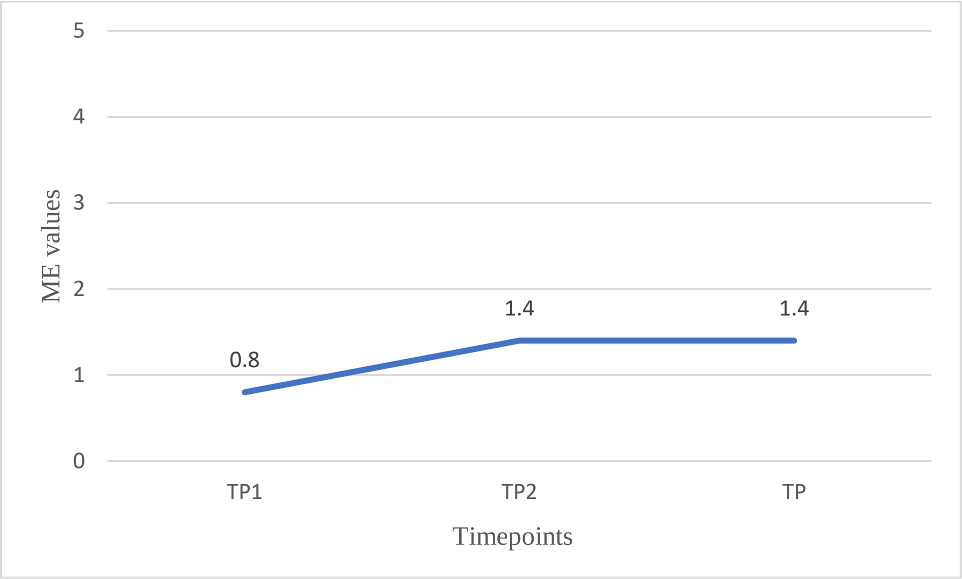

Figure 14: *Changes in average ME of the IG group across time*

In sum, DCM data indicated that the ME of the IG group increased from TP1 to TP2 then remained the same as TP2 at TP3.

6.4 SUMMARY

The chapter has presented and discussed the impact that the intervention had on the wellbeing of *plwd* according DCM data gathered and analysed. The sessions during the IG activity were generally; attendance at the RO sessions ranged from two to five participants compared to attendance at the IG sessions which ranged from six to eight participants. Data from the eight individual maps presented provided evidence that the intervention has the potential to enhance the wellbeing of *plwd* for the most part. During three of the four observations during the IG intervention *plwd* spent most time interacting; During two of the RO observations eating and drinking was the most observed BCC, engaging in the activities was most observed during the other two. This suggests that the students added value to the intervention. Data from the experimental framework showed that the intervention improved the ME of the IG group from baseline. Whilst both groups experienced relative wellbeing during the activity sessions this was higher, although not significantly so, amongst the IG group. The findings presented in this chapter are encouraging however show a partial picture as one *plwd* was observed each week. The next chapter will draw on the data presented here which will be triangulated with data feedback sheets completed by all participants, and qualitative data gathered during focus groups.

7 CHAPTER 7: PRESENTATION AND DISCUSSION OF FINDINGS ALIGNED TO THE THEORIES OF KITWOOD

The purpose of this chapter is to address the research question:

Does the proposed intervention have the potential to enhance the wellbeing of plwd?

The chapter addresses this by exploring the extent to which the intervention upheld the personhood of *plwd* and how this impacted their wellbeing. The chapter focuses on timepoint 2, to explore the participant experience during the activity sessions. To provide a broad picture the amalgamated data from the individual maps was triangulated with DCM notes, and findings from the feedback sheets and focus groups; the triangulation process followed is discussed in detail in Chapter 5. The findings which align with theories of wellbeing and psychosocial need (Kitwood, 1997a, 1997b) will be presented. Kitwood's framework (1997a, 1997b) will be used to help add further theoretical interpretation to the findings.

Data from the individual maps presented in Chapter 6 was amalgamated. As shown in Table 26 the number of Timeframes that were mapped during each activity ranged from 19 during the indoor gardening to 23 during the ice cream session. Eighty-four timeframes were mapped in total during TP2.

Table 26: *The amount of time mapped in TP2 during the research*

Activity	RO Intervention		IG Intervention	
	Time	TF	Time	TF
Ice cream	45 minutes	9	1hr 10mins	14
Fruit salad	1hr	12	50mins	10
Indoor Gardening	45mins	9	50mins	10
Sandwich Making	50 mins	10	50mins	10
Total	3hrs 20 mins	40	3hrs 40 mins	44

7.1 INDICATORS OF WELLBEING/ILLBEING

As illustrated in Table 27 *plwd* spent 96.3% of their time in positive ME; they appeared alert with a neutral facial expression (+1) for 59.5% of the time, happy and engaged (+3) for 30.9% of the time, and very happy and engaged for the remainder of the time (5.9%). The remaining 3.6% of the time was spent in ME-1. Using the DCM data an overall Average ME score for *plwd* during TP2. This was 1.8. which represents a level above neutral, which indicates relative wellbeing.

Table 27: *The mood and engagement of people living with dementia during the activity sessions*

	-1	**+1**	**+3**	**+5**	**Total**
Number of Timeframes	3	50	26	5	84
Percentage of time	3.6%	59.5%	30.9%	5.9%	

Findings from participant feedback forms completed by residents, *plwd* and students presented in Table 28 also showed a general feeling of wellbeing amongst participants. For consistency, each of the mood categories on the feedback sheets were allocated a numerical value similar to that of DCM: 'a bit sad' was allocated -1, Ok was allocated +1, happy was allocated +3, and very happy was allocated +5. Participants reported feeling in a positive mood (+1, +3, or +5) after the activity sessions in 34 of the 35 responses (97%), one response (3%) indicated that the participant felt a little sad.

Table 28*: Results of the feedback form responses*

Activity	A bit sad (-1)	OK (+1)	Happy (+3)	Very happy (+5)	Total completed
Total	1	2	15	17	35
Percentage of responses	2.5%	6%	43%	48.5%	

The feedback sheets were completed by all groups of participants (residents, students and *plwd*) and were not measuring exactly the same construct as DCM however the percentage of participants experiencing positive mood was similar. DCM found that *plwd* experienced positive mood in 97.7% of the observations completed during the activity sessions, data from feedback sheets indicated that participants experienced positive mood immediately after the activity sessions in 97.5% of the cases. Differences were found in the sub categories; the ‘ok/ +1’ option was the least reported on the feedback sheets but most observed using DCM; conversely, of the positive replies, ‘very happy’ was the most chosen response on the feedback sheets, accounting for 17 of the responses (48.5%) but was least observed using DCM representing 5.9% of the time.

A general feeling of wellbeing experienced by *plwd* was also evident from the focus group extracts. Participants spoke of a general enjoyment of the intervention, which was observed by the care staff. Enjoy/enjoyment and derivatives of it such as like/love featured highly in the focus group transcripts; showing pleasure and positive mood, were identified by Kitwoon (1997) as indicators of wellbeing.

Wellbeing was illustrated at the beginning of the participant focus groups, when pictures of the food that had been prepared, were presented to participants with verbal descriptions of them, as a prompt. A resident (Ppt 5) from the RO group, and a *plwd* (Ppt 12) from the IG group responded with a few short comments, which were clearly positive and showed their enjoyment. Ppt 5 commented on each of the individual activities:

> Researcher: Yea so we did an ice cream mix and then we planted some cress so we did one with uh kitchen towels and some soil and then we made a fruit salad [….]
>
> Ppt 5 (resident): lovely […..]
>
> Researcher: we made a sandwich with the cress
>
> Ppt 5 (resident): Beautiful

Ppt12 also made short but positive comments indicating that they had enjoyed the fruit salad and the cress:

> Researcher: And then we did a fruit salad
>
> Ppt 12 (*plwd*): oh yes that was nice
>
> Researcher: yea you liked the fruit salad?
>
> Ppt 12 (resident): that was nice, I liked the fruit salad--
>
> Researcher: …….and then we […….] planted some cress
>
> Ppt 12 (*plwd*): lovely

They said a little more about the ice-cream, indicating that they had enjoyed eating it, and finished by stating that they had enjoyed all of the activities because they liked food.

> Researcher: […] we tried some ice-cream, didn’t we?
> though it was a little bit runny….
>
> Ppt 12 (*plwd*) : enjoyable, it tasted lovely […..]
>
> Ppt 12 (*plwd*) : I like food see so I like everything

Participant 10 also responded positively to the pictorial prompts but in a more neutral tone. When I stated that the ice-cream mix had not thickened up as was hoped Ppt 10 stated that it was not as bad as I had described. This comment was a supportive one which illustrates social sensitivity (empathy), which is one of the 12 indicators of wellbeing as outlined by Kitwood (1997)

> Researcher: Let’s have a look We did some….we tried some ice-cream didn’t we?
>
> Ppt 12 (*plwd*) : Yea, cough
>
> Researcher: Though it was a little bit runny
>
> Ppt 12 (*plwd*): cough
>
> Researcher: It didn’t go
>
> Ppt 10 (*plwd*): Oh, it wasn’t that bad

The participant appeared to remember the indoor gardening by commenting as the pictorial prompt was shown:

> Researcher: …..and then we
>
> Ppt 10 (*plwd*): oh yes I put that in, yes
>
> Researcher: planted some cress

However, they were unable to recall the fruit salad:

> Researcher: And then we did a fruit salad [….]
>
> Ppt10 (*plwd*): I don’t remember having it …that one

Or recognise the sandwiches:

> Researcher: planted some cress and then we made some sandwiches
>
> Ppt 10 (*plwd*): oh, they didn't look like sandwiches

In summary, comments made by Ppt 5, 10 and 12 in response to pictorial prompts indicated relative wellbeing.

In response to questions asked during the focus groups Ppt 5 stated that they had experienced great pleasure.

> Ppt 5 (resident): But I am glad I came met you all and gave me nice ideas things very interesting
>
> Facilitator: Ah good
>
> Ppt 5 (resident): very very interesting [….] I've enjoyed it thoroughly

RO care staff had seen the enjoyment that Ppt 5 had expressed.

> Ppt 7 (carer): …. Ppt 5 has thoroughly enjoyed
>
> Ppt 8 (carer): yea […]

During the IG focus groups Ppt 12 stated that they had enjoyed everything about it.

> Researcher: can you tell me any of you if there was anything that you particularly liked?
>
> Ppt 12 (*(plwd):*): I liked it all
>
> Researcher: you liked it all
>
> Ppt 12 ((*plwd*): yes, I thought they were all nice

Even when I asked them if there was anything that they did not like *plwd* 12 said no:

> Researcher: can you tell me anything you didn't like was there anything you didn't like about any of this?
>
> Ppt 12 (*pwld)*: I can't mention one thing

Once again, the comments made by Ppt 10 were more neutral:

> R: How did you feel during the activities?
>
> P10 (*plwd*): well, nothing really, I thought it was quite good really you know

Although the comments made my ppt 10 were neutral, care staff felt that both Ppt 10 and Ppt 12 had particularly enjoyed themselves.

> Researcher: could you tell me then what you think the residents thought of the activities?
>
> Ppt 18 (carer): I thought that they enjoyed it um especially Ppt 10 and Ppt 12
>
> Ppt 17 (carer): yea
>
> Ppt 18 (carer): *They* was afterwards they were um I thought (Ppt12) really cus *they were* talking about it a lot afterwards and I was asking *them* 'how did that go?' 'Did you enjoy yourself?' and *they were* like 'yes'

The DCM data gathered during observations of Ppt 10 and Ppt 12 which are presented in Figures 9 and 10 reflected the comments made by care staff. Ppt 10 spent most of their time during the fruit salad session in ME+3, while the ME of Ppt 12 fluctuated between +3 and +5 for most of the indoor gardening session.

There were however some instances of illbeing observed during the mapping. As illustrated in Table 27 *plwd* spent 3 timeframes in negative ME (-1). Two were associated with putting the gloves and apron on ready for the activities, the third was experienced the *plwd* was not provided with attention (albeit briefly). A failure to meet an evident need for contact is described by Kitwood (1997b) as withholding, which he states will result in illbeing, which is illustrated in this example.

During the focus groups RO care home staff discussed a couple of instances when *plwd* became disengaged during the intervention.

> Researcher: um yea can you tell me about the resident's mood or behaviour during the intervention? again what did you see?
>
> Ppt 7 (carer): A couple of them did lose a bit of concentration, didn't they? But uh once you got to the end of the product, I think you got their attention span back again

When questioned further about this the staff stated that the *plwd* had become disengaged during the indoor gardening session when looking at and discussing the reminiscence materials before the indoor planting started. Care staff felt that the participants wanted to start the activities rather than simply reminisce, and suggested that the reminiscence was incorporated into the activities rather than be included as a separate 'warm up' activity before the planting. After receiving this feedback, the sessions were adjusted as care staff had suggested which they felt resolved this issue:

> Researcher: yea and that and I was interested to hear you say that they lost attention anything that you noticed when they did that or
>
> Ppt 7 (carer): I think it was when we was discussing things first and doing the reminiscence because
>
> Researcher: mmm
>
> Ppt 7 (carer): they wanted to get stuck in [……]
>
> Ppt 8 (carer): so I'll be honest after that week then we did go to 'this is what we're gonna do' and talking while we were doing
>
> Researcher: yea
>
> Ppt 8 (carer): and you were it was different
>
> Researcher: yea
>
> Ppt 7 (carer): yea
>
> Ppt 8 (carer): wasn't it?

A member of care staff from the IG group stated that IG *plwd* lost interest during the first activity session as the session was long, due to the number of preparations that were required, and interruptions experienced.

> Researcher: lovely so what was your general impression of the activities……. for example, the length of the activities either weekly or four weeks what were your impressions of the length of the sessions?
>
> Ppt 17 (carer): um to be honest I think of the first one because we were all new to each other was a little bit long and I found that they did lose interest

In sum; Taken together, the DCM data, participant feedback sheets and focus group comments suggest that participants generally experienced wellbeing during the intervention, particularly one resident (Ppt 5) of the RO group and two *plwd* of the IG group (Ppt 10 and 12). Although there were a few examples of disinterest, and discomfort experienced by *plwd* they enjoyed the intervention for the most part.

Kitwood stated that wellbeing for *plwd* is not about the strength of the feeling but is represented by experiencing more of the indicators of wellbeing than illbeing over a period of time, which was the case.

7.2 MAINTENANCE OF PERSONHOOD

As discussed in Chapter 3 section 5 Kitwood (1997) identified five psychological needs of *plwd*; attachment, occupation, inclusion, identity and comfort, which taken together represent a central need for love, which are at the core of good care, and maintain personhood. These five domains can be traced through the data gathered during this study. The following section will outline the ways in which personhood was upheld and the impact of this on the *plwd.*

7.2.1 Attachment

The intervention design addressed this need by providing *plwd* with the opportunity to form fresh attachments and reinforce existing ones with other participants within the care home during the RO intervention, and with students from the wider community, during the IG intervention. The data from the study illustrates this dimension of need, in four areas; i) a desire for more attention amongst some *plwd*, ii) enjoyment that *plwd* experienced meeting new people and creating new attachments, iii) high levels of social interaction, and iv) wellbeing experienced as a result of social interactions.

The focus group findings illustrated the relevance of Kitwood's concept of need as "attachment". Evidence of a need for attachment was shown in the findings. Comments from IG carers described a need for attachment; care staff said that ppt 9, 10 and benefit from more attention:

> P17 (carer): yea yea because (*name removed*) and (*name removed*) can be quite competitive can't they for attention so uh with their one on one
>
> R: yea
>
> P18 (carer): yea
>
> P17(carer): And I think (*name removed*) *they* benefits from
>
> P17 (carer): yea
>
> P18 (carer): *they* benefits from the extra attention doesn't *they*
>
> P17 (carer): yea

One resident from the RO group and one *plwd* from the IG group spoke of the enjoyment that they experienced meeting, and interacting with others during the intervention. The resident was referring to the other participants, care home staff, and the research team:

> Ppt 5 (resident): But I am glad I came met you all

Ppt 12 spoke about the joy they experienced meeting and engaging with the students.

> Ppt 12 (*plwd*): No I enjoy I enjoy I enjoy meeting people too I thought it was nice
>
> Ppt 13 (student): yea
>
> Ppt 12 (*plwd*): everybody got different views haven't they and I think it's nice
>
> Ppt 10 (*plwd*): yea haven't we
>
> Ppt 12 (*plwd*): We shared them

They spoke about the pleasure that they had experienced in sharing different views, in a care home setting where residents knew everything about each other:

> Ppt 12 (*plwd*): and it's been nice meeting different people *aga*in yea [….]
>
> Ppt 12 (*plwd*): so you know it's part and pleasure of life isn't it (*unclear*) it gets very stuck down with the same people all the time with them can't you?
>
> Researcher: you can
>
> Ppt 12 (*plwd)*: cus you know what they're thinking and they know what you're thinking too you know it's one of those things that happen in life but [….] nothing wrong with it it does get it's nice when you meet new people innit
>
> Researcher: very nice
>
> Ppt 12 (*plwd)*: yea I think so

They acknowledged the attachments that they had with other residents, but took pleasure in making new ones. Participant 10 did not comment on this but carers noticed that the attachment to students was of particular interest to *plwd* 10 too:

> P17: would enjoy the one-on-one attention
>
> R: right
>
> P18: yea I
>
> P17: Wouldn't interact ... didn't interact with the other residents but liked the one on one
>
> R: so you think *they* interacted during these activities;
>
> R: yes with the students

Introducing student visitors increased the opportunity for the *plwd* involved to make new contacts. This concurs with findings from previous research. Lawrence et al. (2012) found that interventions that brought volunteers into the residential setting were particularly useful for forming relationships beyond those of the residential setting. George (2011) found that relationships with people from helped mitigate feelings of social exclusion. This is important because care home residents are at high risk of social isolation (Cahill 2018 cited in Villar et al., 2021, p.298).

The intervention was designed to be delivered over four weeks, the aim of this was to facilitate the development of relationships and enable attachments to form. The Care home staff commented on the length of the intervention; they felt that the timescales offered benefits for the *plwd,* allowing them to feel familiar with the visitors. As the weeks passed some *plwd* asked if anyone was coming back, which suggests a level of bonding which is incorporated in Kitwood's (1997) conceptualisation of attachment.

> Ppt 18 (carer): and because it was every week wasn't it once a week um it was like regular faces for the residents
>
> Ppt 17 (carer): yes
>
> Ppt 18 (carer): as well so they were a bit more familiar with you coming in and
>
> Researcher: mmm
>
> Ppt 17 (carer): I've lost my point I'm sorry (*laughter*)
>
> Researcher: yea
>
> Ppt 18 (carer): yea If I found after the first session they discussed it cus it was on a Monday and they kind of only one mentioned it again the day after It was talked about a lot afterwards on the Monday um only one

> mentioned it on the Tuesday but I found as the weeks were going on and you weren't here for the I was here for the first two that they were discussing it is is anybody coming back again so they were kind of remembering but only two of out of the four

The data shows that the notion of "attachment" as forwarded by Kitwood may need time to develop. The length of IG interventions involving *plwd* in a care home setting delivered in a series of sessions may offer greater opportunity for attachments to develop, than interventions delivered in a single session.

High levels of interaction were evident during the activity sessions. *Plwd* enjoyed their established relationships, and developing new ones. The amalgamated DCM data shown at Table 29 illustrates that interaction with others (A) was the behaviour that *plwd* engaged in most during the activity sessions.

Table 29*: Behaviours that plwd engaged in during the activity sessions*

BCC	A	B	D	F	G	K	L	O	P	V	Total
Total number of timeframes	**33**	6	7	15	2	2	2	1	4	12	84
Percentage of time	**39.3%**	7.1%	8.3%	17.9%	2.4%	2.4%	2.4%	1.2%	4.8%	14.3%	

High levels of interaction were mentioned by one of the care staff from the RO group;

> Ppt 8: (carer): and that lovely all the little between everybody little chitty chats going on and they were really enjoying

Positive wellbeing experienced during social interactions can be illustrated well using the DCM data gathered. In total *plwd* spent 33 Timeframes interacting, 12 in ME+1, 18 in ME+3, and 3 in ME+5. This is also illustrated in the individual maps created for Ppt3 in the RO group and Ppt 9 in the IG group. Both participants experienced ME +1 during the majority of the activity session, which increased on a few occasions as a result of interactions with others. Ppt 3 smiled and winked in response to a joke made by another participant, and while they talked to the activities facilitator as the session came to a close. This can be seen on Figure 6. Ppt 9 appeared relaxed and engaged

ME+3 as they talked to their student partner who was asking if they would like to engage with the ice-cream making tasks, and when they engaged with the wider conversation within the group. This can be seen on Figure 8.

However, Ppt 5 stated that would miss the company when the intervention was over:

> Researcher: And I wonder then how you feel now we've finished the activities
>
> Ppt 5: I'm gonna miss it
>
> Facilitator: Ah
>
> Researcher: Ah
>
> Ppt 5: I tell you what I'm gonna miss it a lot
>
> Researcher: Ah
>
> Ppt 5: I look forward to coming along to meet you all

Which was noted by the care staff:

> Ppt 8: …(*name removed*) has thoroughly enjoyed
>
> Ppt 7: yea and
>
> Ppt 8: as last week I left at quarter to five and *they* 's still sitting there still having a cup of tea and *they* 's just enjoying up up yer
>
> Researcher: yea
>
> Ppt 7: yea
>
> Ppt 8: wasn't *they* ?
>
> Ppt 7: yea
>
> Researcher: and
>
> Ppt 8: They've all said they are going to miss you
>
> Researcher: Ah

This is a challenge associated with short IP programmes; that older adult may feel more isolated if no other replacement activities fill the gap (Welsh Government, 2019). The care home which facilitated this intervention had a varied and full programme of activities, as described by care staff in the following chapter, which addressed this issue, however this finding illustrates the importance of such interventions being included in university curricula (Service-Learning programmes).

In conclusion: Kitwood's concept of attachment was supported in the findings. Care staff described a need for attachment amongst *plwd* which the intervention met. Participants said that they had enjoyed meeting new people and forming attachments, and bonding was reflected in high levels of interaction found in DCM data and focus group comments. Social interactions were generally experienced as pleasurable, and associated with positive mood, which are both indicators of wellbeing, according to Kitwood (1997).

7.2.2 Occupation

Kitwood (1997b, p.20) stated that occupation means; 'to be involved in the process of life in a way that is personally significant, whether this consists of action, reflection, or relaxation'. The intervention design addressed this need by providing *plwd* with meaningful occupation; preparing and sharing food. The data from the study illustrates this dimension of need, in four areas; i) a desire for to help amongst some *plwd*, ii) good levels of engagement with the activities, iii) wellbeing experienced whilst engaging in the activities and iv) observation as occupation.

Kitwood (1997) stated that the need for occupation in *plwd* is evident by a desire to help, and an eagerness to take part in activities. Both of these instances were found in the data. A need for occupation was clearly demonstrated when Ppt 1 expressed enthusiasm for joining in similar activities if offered in the future;

> Researcher: Would, would you join in similar activities again
>
> Ppt 1 (*plwd*): Yes, indeed anything goes I'll join
>
> Researcher: That's lovely
>
> Ppt 5 (resident): and I will

DCM notes also included evidence of participants wanting to help. For example, Ppt 2 helped clean up after the RO activities, and Ppt 12 helped put the tablecloth on during the IG activities.

Good engagement levels were found with preparing and sharing the food. Amalgamated DCM data (see Table 29) showed that eating and drinking was the second most popular activity that *plwd* engaged in during the observations, preparing the food (V) was the third. Some of the F timeframes were associated with drinking refreshments provided by care home staff during the activities. Four of the six *plwd* mapped (Ppt 1, 2, 9, 12) engaged in preparing the food. Care staff from the RO group noticed that participants had preferred being involved with the activities than talking:

> Ppt 7 (carer): yea uh I think um they preferred actually doing the practical side as opposed to talking about it other things but they got involved um enjoyed

And were eager to start the indoor gardening activities:

> Ppt 7 (carer): they wanted to get stuck in
>
> Researcher: mmmm
>
> Ppt 7 (carer): but once they did get stuck in especially with like the planting everyone wanted to get the water in and get the you know
>
> Researcher: yes
>
> Ppt 7 (carer): wanted to do a little bit

While care staff from the IG group had observed *plwd* engaging with the ice cream making:

> Ppt 17 (carer): um but yea they all had a go at it didn't they and they all
>
> Researcher: they did

Wellbeing was associated with both aspects of occupation, preparing and sharing food. *Plwd* spent 12 Timeframes preparing the food, all of which were experienced in positive ME; 5 in ME+1, 5 in ME+3, and 2 in ME+5, and 15 timeframes eating and drinking: 11 in ME+1 and 4 in ME+3. Interestingly both of the ME+5 timeframes were experienced during the indoor gardening activity (which can be seen in Figure 5 and Figure 10). For both *plwd* who enjoyed gardening this was a very enjoyable activity. This finding is supported by previous research which has found indoor gardening engaging for *plwd* (Lee & Kim, 2008).

Findings from the focus group indicate that participants had found the activities meaningful. One *plwd* and both sets of carers mentioned the significance for *plwd* of being able to eat what they had made. Ppt 12 said that they had enjoyed making the fruit salad and eating it once prepared.

> Researcher: what was it you liked particularly then about the fruit salad?
>
> Ppt 12 (*pwld)*: I liked it all being prepared didn't we

> Ppt 13 (student): yea
>
> Ppt 14 (student):
> yea
>
> Ppt 12 (*pwld)*: and we could eat it
>
> Ppt 13 (student): yea

Carers from the RO group highlighted the enjoyment experienced by *plwd* because they could eat what they had made:

> Ppt 7 (who): they enjoyed the ones they enjoyed they could watch that growing on a daily basis but ones like the fruit and we're going to eat it there we are we're making cress sandwiches and we're going to eat it
>
> Researcher: yea
>
> Ppt 7 (carer): yea [….]
>
> Ppt 7 (carer): something from start to finish

Carers of the IG group also highlighted the same point:

> Ppt 18 (carer): ……then they were getting mucked in with it so and then they get to eat eat it afterwards and they they made something themselves and they get to enjoy it

Kitwood (1997b) suggested that a loss of self-esteem will result if a need for occupation in *plwd* is not met. Engagement with the preparation of food which they were going to eat appeared to link to self-esteem/self-respect, which is an indicator of wellbeing (Kitwood ,1997).

DCM data showed that *plwd* engaged with the intervention to varying degrees and in different ways. Two *plwd* (Ppt 3 & Ppt 10) chose not to engage with the activities but watched and chatted throughout the session. They were both mapped once, during the fruit salad sessions. Neither participant engaged in the activities associated with making the fruit salad but both took some fruit and ate it whilst the fruit salad was being made, and both participants ate a bowl of fruit salad when it was completed. Care home staff also noted that Ppt 3 enjoyed eating the food although they chose not to engage in preparing it, and discussed this during the focus group:

> Ppt 8 (carer)*:* so even though they didn't do a lot of the stuff they sat and was quite happy then to eat the sandwiches to eat the fruit salad or

Although observation may not satisfy the term ‘occupation’ generally, it would fit with Kitwood’s (1997b, p.20) description that occupation in relation to *plwd* consists of: ‘action, reflection, or relaxation’. Observation was most regularly mentioned as an occupation by *plwd* interviewed in a study completed by Kaufmann and Engel (2014) which explored Kitwood’s philosophy of needs (1997b). Carers of the RO intervention illustrated that some *plwd* enjoy activities by simply watching;

> Ppt 8 (carer): we do it in here, yet but like they might have a film night downstairs and they might like have a pub night and if they don’t want to go down we get the with the board games out yer some of them depending how they are might not join in draughts or cards they might do but they might enjoy just watching it could be us playing the games with them helping them along on one isn’t it?

and made it clear during the focus group that Ppt 3 was engaged with the intervention, stating that the *plwd* would have left the table if they were not engaged:

> Ppt 8 (carer): [Ppt 3] to sort of thing in there *they* enjoyed was watching
>
> Ppt 7 (carer): yea
>
> Ppt 8 (carer): so even though you asked *them they* didn’t feel like pressured that you know oh come on you’ve got to join in
>
> Researcher: yea
>
> Ppt 8 (carer): Cus you could see they didn’t move and as I said that’s one of the signs if *they* wasn’t happy with what we were doing *they* would have got up and walked away
>
> Researcher: yea
>
> Ppt 8 (carer): so even though *they* didn’t do a lot of the stuff they sat and was quite happy then to eat the sandwiches to eat the fruit salad or
>
> Researcher: yea
>
> Ppt 8 (carer): yea?
>
> Ppt 7 (carer): yea *they* participated
>
> Ppt 8 (carer): yea so even though *they* might have just sat there and looked *they* was in *their* own way participating
>
> Researcher: yea

This comment from the carers offered an interesting insight to the experience of Ppt 3. The DCM data gathered and presented in Figure 6 suggested that the participant had engaged to a minimal extent, as their facial expression had remained predominately neutral throughout, therefore their ME had been recorded as +1. This data suggested that the participant engagement had been minimal however the insight from the care staff provided during the focus group told a different story, one in which the mere act of remaining at the table had indicated considerable participant engagement.

Although no DCM data was gathered on Ppt 11, IG carers also stated that they had watched, which was what they usually did during activities:

> P17 (carer): I know in one of the sessions (ppt 11) one *they* didn’t really want to participate but I think that was just *they* uh
>
> P18 (carer): *they* wasn’t well at the time *they* had
>
> P17 (carer): yea
>
> P18 (carer): *they* had another issue on *their* mind and are you talking about session 2? With the fruit salad
>
> P18 (carer): no it was the cress one
>
> R: oh right
>
> P18(carer): number 3
>
> P18 (carer): *they* didn’t participate in it but there was something against *they* something that was bothering *them* so *their* mood was a little bit down but if *they* had have participated I think
>
> P17 (carer): mmm
>
> R: But *they* didn’t want to participate that’s fine that’s (unclear)
>
> P18 (carer): But you I think that was just that day cus it’s every day is different for everybody isn’t it?
>
> P17 (carer): um *they* didn’t participate much in session 2 mind did *they* ? Um and I know *their* mind was preoccupied there but
>
> R: and *they* chose not to participate in 3 or 4
>
> P17 (carer): ah right
>
> R: yea
>
> P17 (carer): right ok
>
> R: yea *they* chose not to so that’s

> P17 (carer): yes right
>
> R: That's
>
> P17(carer): Would say most activities that go on will always only sit on the outside and watch

In conclusion: Kitwood's concept of occupation was supported in the findings. A need for occupation was observed which the intervention met. The flexibility of the intervention meant that *plwd* could engage in occupation by preparing the food, sharing it, or simply watching. Relative wellbeing was experienced while *plwd* were preparing and sharing the food, which appeared meaningful and to promote self-esteem for some. This finding illustrates the importance of providing meaningful occupation and flexible interventions for *plwd* in a care home environment.

7.2.3 Inclusion

'Attention seeking, clinging, hovering, protest and disruption (Kitwood 1997, p.94). The data from the study illustrates this dimension of need, in two areas; i) the simplicity of the activities, and ii) fun that was experienced during the ativities. The intervention was designed to address a need for inclusion by providing occupation that matched the ability of the participants, which was perceived as simplicity by participants and care staff.

Participants and carers felt that the activities were enjoyable as all participants were able to become involved if they chose to; the simplicity of the tasks was appreciated. A resident (Ppt 5) said that they liked the activities because they were so simple,

> Researcher: I wonder if you could tell me how you felt when we did some of these things when we made the ice cream or made it and tasted it and made these and tasted them Do you remember how you felt when we did them?
>
> Ppt 5 (resident): I felt wonderful….learning it I did such an easy idea you'd never think of unless you were shown

They mentioned this several times during the focus group

> Researcher: so, could you tell me anything you liked about any of that that we did
>
> Ppt 5 (resident): How can I explain it now I'm not very good at explaining, the fruit salad give me good ideas which I would of never

> thought of to do so easy and plenty of everything fruit and so nice it was tasty Ah it was lovely with Ideal very nice

and when asked what they would like in the future they said ‘something simple’.

> Researcher: And I wondered then do you have any ideas we could use if we do it again? Is there anything that you like to make? That? Any ideas? I was wondering what other people might like to make, anything we could have tried? Anything?
>
> Ppt 5 (resident): simple, something simple

RO care staff identified the ‘simplicity’ of the activities as being a key factor in participant enjoyment:

> Ppt 7 (carer): there was nothing complicated
>
> Ppt 8 (carer): yea keeping it simple was good yea

Plwd were capable of completing the task:

> Ppt 7 (carer): quite simple things for them so they didn’t feel like even though maybe *they* didn’t want to join in *they* was quite capable of doing it if *they* wanted

Which *plwd* felt:

> Researcher: yea
>
> Ppt 7 (carer): maybe we’ll do this bit and you can do the other bit
>
> Researcher: yea
>
> Ppt 7 (carer): so, I think they felt it wasn’t out of their range
>
> Ppt 8 (carer): I know
>
> Researcher: good

Kaufmann and Engel (2014, p.15) state that the need for inclusion is fulfilled when an individual with dementia has a feeling of recognition, feels accepted, and equal’ (K & E, 2014, p.15). Lawrence et al. (2012) found that taking part in activities with other residents provided residents with a valued sense of inclusion. A quote from one of the

IG care staff suggests that *plwd* in this study experienced a sense of equality and inclusion;

> P18 (carer): I liked how they like all were able to when you were doing the fruit salad, they were cutting things making things um and then with the seeds they were pressing em down and I think that getting them to do it themselves I think it was nice for them as well cus they were instead of someone else sitting there going ah let me just do this then they were getting mucked in with it

Having fun together supports a sense of inclusion (UOB. p.39), which was a feature of both interventions. This was most notable during the RO intervention when a resident playfully sprayed water over the facilitator and everybody laughed. This resulted in ME+5 for the *plwd* observed (Ppt 2, see Figure 5). Ppt 12 stated that they had found preparing the fruit salad fun:

> Researcher: what was it you liked particularly then about the fruit salad? …[…..]
>
> Ppt 12 (*pwld)*: It was fun doing it

In fact, they felt that they had fun during every activity session, and the students agreed:

> P12 (*plwd*): I've enjoyed the series and that's it (unclear here)…too and it's been a bit of fun every time hasn't it?
>
> P13 (student): yea
>
> P14 (student): yea
>
> P12 (*plwd*): there's been a lot of laughter and that's lovely I think

They also expressed humour during the focus group, which is an indicator of wellbeing (Kitwood, 1997).

Ppt 12 said that they had liked the intervention because they loved food, all food and joked that they had put on weight as a result of their engagement with the intervention.

> Researcher: can you tell me anything you didn't like was there anything you didn't like about any of this?
>
> Researcher: um how are you feeling now? Now we're
>
> Ppt 12 (*pwld)*: I think I'm fatter than what I was

Another example of humour was observed during the mapping of Ppt 10. During the fruit salad activity session, the participant ate a banana and put one on the head of another participant, laughing while they did so. This was accompanied by a ME of +3 (see figure 8) which supports Kitwood's (1997b) assertion that humour is an indicator of wellbeing.

In sum, the simplicity of the activities, and the fun involved promoted inclusion, supported personhood, and indicated wellbeing amongst the participants.

7.2.4 Identity

The intervention design addressed this need by providing the opportunity to talk about past activities, previous interests, social and occupational roles, and possibly the loss of them (Reminiscence). The opportunity for reminiscence was provided in a number of ways; with pictures, ingredients, and activities. The data from the study illustrates this dimension of need well, in these areas; *plwd* engaged with reminiscence, and provided an insight into their identity by discussing their likes and dislikes.

In the DCM data two timeframes were spent predominately reminiscing (see Table 29), both were at the beginning of the indoor gardening sessions. Ppt 2 spent some time looking at the reminiscence materials (pictures of traditional lawnmowers and seed packets) that the research team provided. For Ppt 12 the gardening provided a link to their past, as they talked about their previous gardening experience. Both *plwd* ME+1 as they were reminiscing.

The focus group findings also highlighted the relevance of Kitwood's concept of identity as a need: One resident (Ppt 5) reminisced during the focus group; talking about their 'previous life' and how they had used to cook:

> Ppt 5 (resident): I used to do lots of cooking once, making pasties and all that you know, cakes, puddings, tarts I wouldn't know the recipe for them now before it was all in my head but time to think what would you like in the future?

The activities themselves prompted reminiscence too, by providing links to the past. Care staff from the RO intervention felt that participants particularly enjoyed the 'war-time' ice-cream as it used ingredients that were likely to be familiar to them:

> Ppt 8 (carer): even with the ice cream it was using a product that they would have used years ago
>
> Ppt 7 (carer): yea
>
> Ppt 8 (carer): and cus it was an old recipe
>
> Ppt 7 (carer): quite
> yes
>
> Ppt 8 (carer): I think it was more to their…uh liking

IG care staff also highlighted the traditional recipe and noted that all participants had engaged with the activity.

> Ppt 17 (carer): I would have thought maybe one or two of them would have known how to make the ice cream cus it was an old-fashioned recipe wasn't it?
>
> Researcher: *yea*

Some participants expressed their identity by talking about their likes and dislikes Ppt 1 said that they liked fruit salad

> Ppt 7 (carer): was it the fruit salad? …..you're on about?
>
> Ppt 1 (*plwd*): yes
>
> Ppt 7 (carer): [……]
>
> Ppt 1 (*plwd*): that's right I like I like a salad

Ppt 12 also stated that they had enjoyed the fruit salad and added as it is a favourite of theirs.

> Ppt 12 (*plwd)*: cus I did love em all I've got to say that
>
> Ppt 13 (student): I liked the fruit salad
>
> Ppt 14 (student): I liked the fruit salad
>
> Ppt 12 (*plwd*): Oh and and I do I love fruit salad it's lovely well of course it's my favourite

In fact Ppt 10 and 12 stated that they liked food in general:

> Ppt 12: I like food see so I like everything
>
> P12: a nice bit of cake or something
>
> R: like a little bit of cake?
>
> P10? (unclear) I like food

> P12: I like food too I've enjoyed it all all that I've had fair play

Interventions which provided participants with the opportunity to talk about past activities, previous interests, social and occupational roles, and possibly the loss of them, allow participants 'to express their identity' (Harmer & Orrell, 2008).

In conclusion: the data suggests that participants enjoyed the chance to express their identity, which was provided by the intervention. This impacted their wellbeing positively, particularly for participants 2, 5 & 12.

7.2.5 Comfort

The data from the study illustrates this dimension of need well, in these areas; *plwd* felt comfortable in their surroundings (their comfort zone), and having 1:1 support during the IG intervention. DCM data suggested that participants felt comfortable for the most part which was supported by comments made by participants and care staff. Participants stated that they felt relaxed during the intervention, which was observed by care staff who felt that this was because the intervention was completed in the participants home, and that participants were well supported by other residents, staff and students, in small groups.

RO Care staff felt that participants were relaxed during the intervention because it was completed 'at home' where everything was familiar.

> Ppt 8 (carer): I think (*name removed*) enjoyed it because it was on the unit and it seemed familiar surrounding
>
> Ppt 7 (carer): cus they don't always like going off the unit much
>
> Ppt 8 (carer): nah
>
> Ppt 8 (carer): cus they …. Especially …..at the moment as they went downstairs for the celebrations the other day they came back tearful there was something else went down happy to go happy when they are there but when they have come back tearful then when you're doing it on the unit
>
> Ppt 7 (carer): they are fine
>
> Ppt 8 (carer): They're in their own environment

The exact room for the intervention was chosen in collaboration with the care home managers. Both managers felt that the 'unit' where the participants lived was the optimum location as residents would feel comfortable; this was borne out by the results.

Carers stated that *plwd* did not like ‘leaving the unit’.

> Ppt 8 (carer): … we get singers in to and like there’s things go on downstairs these much prefer to have stuff
>
> Ppt 7 (carer):in here
>
> Ppt 8 (carer): in the unit as they don’t I know we’ll be going out for the singalong but I know when we came back…they’ll be in tears after enjoy it when they are there but as soon as they come back they are quite agitated
>
> Ppt 7 (carer): yea as you’ve taken them out of their comfort zone
>
> Ppt 7 (carer): yea
>
> Ppt 8 (carer):yea

Participants of the IG intervention (*plwd* and students) said that they had felt relaxed during the activities: ppt 10 agreed with students.

> Researcher: How did you feel during the activities?
>
> ….[….]
>
> Ppt 13 (student): Relaxed yea Relaxed Relaxed …and happy
>
> Ppt 14 (student): yea
>
> Ppt 10 (*plwd*): yea

The group size and structure were also identified as key factors which resulted in participant enjoyment of the intervention. The RO care staff felt that the small group size was important:

> Ppt 8 (carer): And they didn’t feel not that anybody pressures anybody to do anything but I think they felt quite relaxed it was the smaller group rather than the larger group
>
> Researcher: so although there was a big group at the table the fact that they were in
>
> Ppt 18 (carer): They had someone there with them
>
> Researcher: that sort of took away their anxieties..

> Ppt 18 (carer): yea do you think?

and the IG care staff felt that the 1:1 aspect was the most positive aspect of the intervention:

> Ppt 18 (carer): I thought that the one on one with the resident I think that definitely benefitted the residents a lot better because I think they being more comfortable as they had someone there just with them and having them pay attention to everybody at the same time so I think that was like I think that was the best part about it

Lokon, et al. (2017) also found that the 1:1 element was a key factor which enabled relationships to develop during their intergenerational study. However, they stated that interacting with the same partner on a weekly basis over an entire semester was essential to bring about change in the attitudes of students involved in an IG arts programme delivered in long term care settings. The findings of this thesis contradict that as it was not practical to pair up the same student with the same *plwd* each week, however this still resulted in a change in students' attitudes which is discussed in Chapter 8.

In sum, participants generally felt comfortable and relaxed during the intervention, which reduced their anxieties as Kitwood (1997) states, and supports personhood.

7.2.6 Agency

Kitwood (1997b) described Agency as one of four 'sentinel states' which underpin wellbeing in *plwd* however did not refer to it in the list of the indicators of wellbeing or PPW interactions that relate to it. However, Kaufmann and Engel, (2014) suggested that Agency be added to Kitwood's model as an additional 'need'. Choice featured in the findings from the focus groups.

Care staff from the RO intervention mentioned this during the focus groups; they had observed Ppt 5 asking whether there was any Ideal milk to put on the fruit salad, and participants choosing the fruit that they wanted in their fruit salad.

> Ppt 7 (carer): and when we did the fruit salad thing said by yer was oh can we have some Ideal milk
>
> Researcher: yea
>
> Ppt 7 (carer): and so we did get a can of Ideal milk because that's what they would have had with most things

The care staff felt that participants had enjoyed being able to choose what fruit to put in their fruit salad.

> Ppt 7(carer): yea and the fruit salad because not everybody wanted blueberries and somebody didn't want orange so with the three bowls you could um oh how can you say do it so they enjoyed it like I was saying so when the fruit salad comes up like there's oranges in this then maybe they don't all like it […..] that's what they enjoyed was the choice

The choices that were featured in the intervention resulted in what was perceived by RO care staff to be an 'individualised' experience for participants, which they felt was as a reason why participants enjoyed the intervention.

> Ppt 8 (carer): so I think it does pick their spirits up a bit and I think because it was more designed towards them as individuals

A personalised approach is at the core of person-centred care which is discussed in Chapter 3. Kitwood (1997a) stated that successful interventions may provide the perfect conditions for person centred care.

7.3 CHAPTER SUMMARY

This chapter provided a broad picture of the experience of *plwd* and presented evidence of relative wellbeing which was generally experienced by participants during the intervention. The findings support Kitwood's philosophy of needs. The five psychosocial needs of attachment, occupation, inclusion, identity, and comfort were met by providing participants with the opportunity to build relationships and collaborate in preparing and sharing food, in a comfortable environment based on equality, which resulted in relative wellbeing. According to Allport (1954) and Pettigrew (1998) providing members of an ingroup, in this case students, with the same opportunities will result in improvements in attitudes towards an outgroup, in this case *plwd*. The next chapter will discuss the findings of this study which address the potential of the intervention to enhance students' knowledge of, and comfort with *plwd*.

8 CHAPTER 8: PRESENTATION AND DISCUSSION OF THE EXPERIENCES OF STUDENTS AND CARE HOME STAFF

The aim of this chapter is to present the findings that address the following research questions:

> *Does the intervention have the potential to improve the 'dementia knowledge' and attitudes of students?*
> *What challenges may care homes face in implementing the intervention?*

The chapter is in two sections. The first section will draw on the data gathered using student questionnaires and qualitative data gathered during the focus groups to answer the first question. The second section will draw on focus group quotes provided by care staff to explore the second

8.1 EFFECTS OF THE IG INTERVENTION ON THE STUDENTS

Four student questionnaires were completed pre- and post-intervention. The questionnaire consisted of two tasks; the DAS (O'Connor & McFadden, 2010) and a phenomenological task which asked *'when you hear the word dementia, what images come to mind? Please write down 10 words that describe those images'* and which was used in previous research (Harris & Caporella, 2014).

8.1.1 Findings from the DAS scale

The DAS scale is made up of two subscales: comfort and knowledge. The scores which can be reflected in each subscale range between 0-70, and between 0-140 for the overall DAS scale. The raw data gathered from students is shown in table 30. Three students (ppt 14, 15 and 16) reported an overall increase in the DAS scale and in both subscales. The fourth student (ppt 13) reported an increase of 3 in the comfort scale and a decrease of 3 in the knowledge scale, which resulted in no change in the overall DAS score.

Table 30: *Raw DAS scores of students across two time points*

	Overall DAS score			**Comfort**			**Knowledge**		
Participant	TP1	TP2	**Change**	TP1	TP2	**Change**	TP1	TP2	**Change**
13	125	125	**0**	55	58	**+3**	70	67	**-3**
14	121	136	**+15**	56	67	**+11**	65	69	**+4**
15	104*	116	**+12**	43	53	**+10**	61*	63	**+2**
16	96	116	**+17**	43	54	**+11**	53	62	**+9**
Total	446	490	**+44**	197	232	**+35**	249	261	**+12**

**: There is missing data*

Participant 15 did not respond to question 7 at TP1 therefore, all ppt 15 data for question 7 was excluded, and subsequently all data for Q7 was excluded from the analyses. Amalgamated data showed an overall increase in the mean score on the DAS scale and both subscales, with the greatest increase in the comfort subscale. Paired samples t-test were conducted to compare the scores on the overall DAS scale, both subscales, and 19 individual scale items. It is uncommon for results to reach statistical significance in very small samples (Pallant, 2016); however, it is useful to consider the effect size (Kramer & Rosenthal, 1999; Coe, 2002), therefore, effect size calculations were conducted for each t-test. All of these results can be found in Appendix 30.

A statistically significant increase was reported in the comfort subscale. Scores increased from time 1 (*M* = 49.25, *SD* = 7.3) to time 2 (*M* =58.25, *SD*=6.13) *t* (3) =4.50, *p* < .020. The mean increase was 9.00 with a 95% confidence interval ranging from 2.63 to 15.36. The magnitude of the difference in the means was 2.25 which represents a large effect size according to Cohen's d. The analyses found a non-statistically significant increase in overall DAS scores from time 1 (M=106.50, *SD*=12.47) to time 2 (*M* =118.00, *SD* =8.28), *t* (32) =2.81, *p*>.067. The mean increase was 11.50 with a 95% confidence interval ranging from 1.52 to 24.52. The magnitude of the difference in the means was 1.40 which represents a large effect size according to Cohen's d. There was also a non-statistically significant increase in scores on the knowledge sub scale from time 1 (*M* =57.25, *SD* =7.13) to time 2 (*M*=60.00, *SD*= 3.55), *t* (3) = 1.20, *p*>.315. The magnitude of the difference in the means was 0.60

which represents a medium effect size according to Cohen's d. The mean increase was 2.75 with a 95% confidence interval ranging from 4.52 to 10.02. In sum, the t-tests showed a statistically significant increase in the comfort scale. Large effect sizes were reported in the overall DAS scale and comfort subscale, a medium effect size was reported in the knowledge subscale.

As can be seen in figure 15 the greatest increase was in the comfort scale. This was not unexpected as the students were studying Psychology, therefore are likely to have a good knowledge of dementia, which was reflected in their pre-intervention score. The mean scores at TP2 were similar in both subscales; both were high.

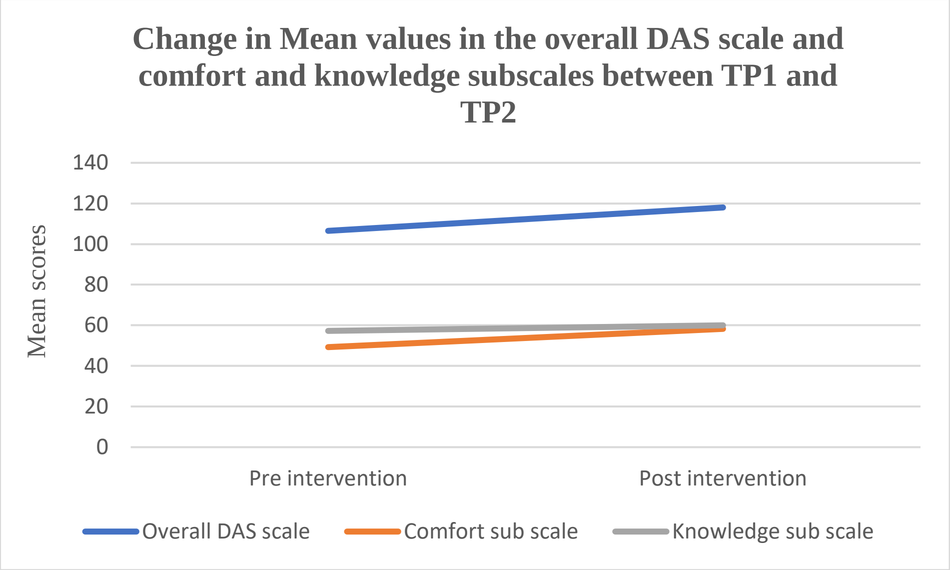

Figure 15: *Changes in average scores on DAS scale across time*

Paired samples t-tests and effect size calculations were also conducted to compare the scores for each of the 19 individual scale items, for which all students recorded data (see Appendix 26). Scores increased for 16 items, remained the same for 2 items, and decreased for 1 item. The effect size of 13 of the 16 items which scores increased reported either a large or medium effect size.

Eight items in the comfort subscale reported either a medium or large effect size change, seven increased, one decreased. The increase in one scale item reached statistical significance. Scale items illustrated with an * were reverse scored items, which means that an increase in scores represented an increase in levels of disagreement with the statement; this is in effect a positive change. Large effect sizes were reported in three items:

Q4. I feel confident around people with dementia

Q8. I am not very familiar with dementia *

Q16. I feel frustrated because I do not know how to help people with dementia *

The statement that resulted in the largest increase and the only change that reached significance was statement 4 ‘*I feel confident around people with dementia*’. Mean scores increased from time 1 (*M* = 3.75, *SD* = 0.5) to time 2 (*M* =5.75, *SD* =1.3), *t* (3) = -4.90, *p* < .016. *This increased in all students, and was the only scale item that did.* Five items reported a medium effect size, four of which represented an increase in scores.

Q2. I am afraid of people with dementia*.

Q5. I am comfortable touching people with dementia

Q6. I feel uncomfortable being around people with dementia *

Q9. I would avoid an agitated person with dementia *

The fifth item reported a decrease in score, this was the only scale item that reported a decrease:

Q1. It is rewarding to work with people who have dementia.

This statement and one of the statements that showed no change (Q12) had the highest scores of all of the scale items, at pre-test, which means that there was little room for improvement.

Six items in the knowledge subscale reported either a medium or large effect size change. Large effect sizes were reported in four items:

Q3. People with dementia can be creative

Q14. People with dementia can enjoy life

Q15. People with dementia can feel when others are kind to them

Q20. Difficult behaviours may be a form of communication for people with dementia

Medium effect sizes were reported in two items:

Q18. I admire the coping skills of people with dementia

Q19. We can do a lot to improve the lives of people with dementia

To summarise, findings from the DAS are encouraging, the score for only one scale item decreased between TP1 and TP2; the scores on all other scale items, subscales, and the overall scale increased, or remained the same. The non-significance reported is likely to be due to a lack of power in this small sample, however the effect sizes are good. Students reported feeling more confident and familiar with dementia at TP2, and believed that *plwd* can be creative and enjoy life

8.1.2 Findings from the phenomenological word task

Findings from the second task; the word task in which students were asked: '*when you hear the word dementia, what images come to mind? Please write down 10 words that describe those images,* also illustrated positive change. Each student generated wordlists of between 7 and 11 words at two timepoints; prior to visiting the care home (TP1), and after the four-week intervention (TP2). This data was amalgamated to produce one list at TP 1 containing 38 words in total, and another list at TP 2, containing 37 words in total (see Appendix 29).

The focus of the lists moved from negative to positive between TP2 and TP2. Table 31 illustrates the number of words in each of three categories; negative, neutral, and positive, recorded at both Timepoints, and changes found between the timepoints. As can be seen, no positive words appeared in the list at TP1. In contrast, most of the words at TP2 were positive.

Table 31: *Students' Attitudinal responses in the phenomenological word task*

	TP1	TP2	Change
	Number of words		
Negative	21	7	-14
Neutral	17	12	-5
Positive	0	18	+18

As Figures 16 and 17 illustrate the change between the timepoints represent a decrease in negative words of 36.4%, and an increase in positive words of 48.7%.

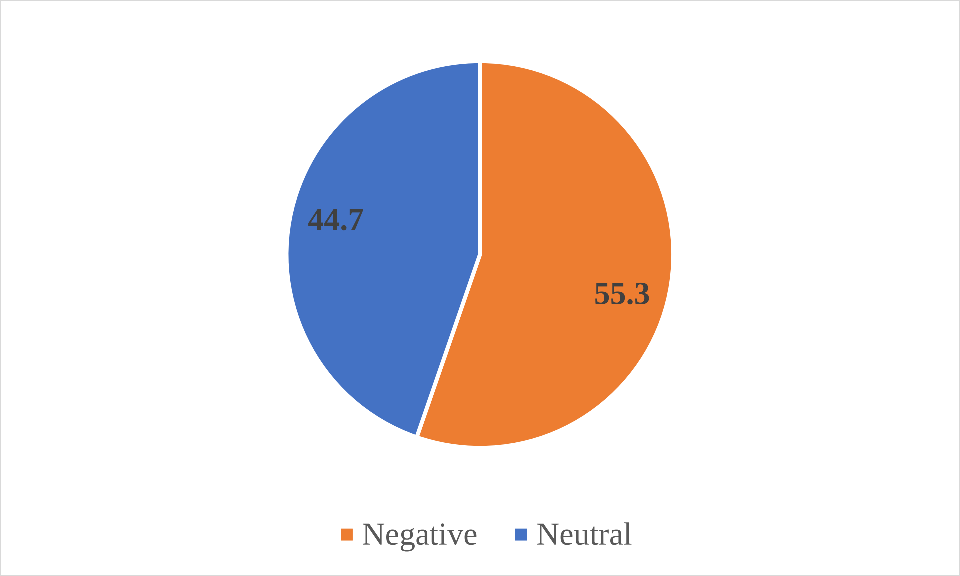

Figure 16: *Percentage of positive, neutral and negative words listed at Timepoint One*

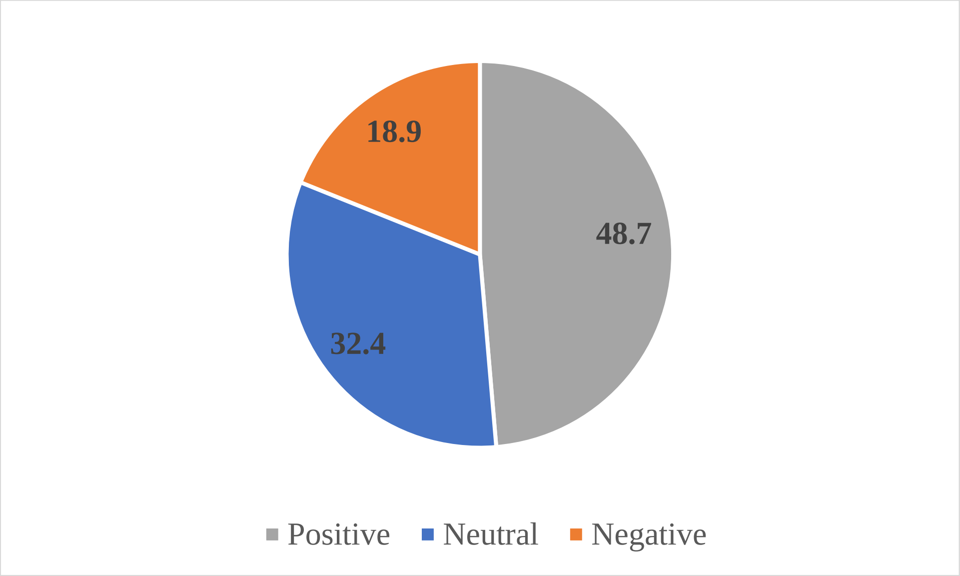

Figure 17: *Percentage of positive, neutral and negative words listed at Timepoint Two*

Number of positive/negative/neutral words: These findings support the results from previous studies. Sabat (2011) used a similar word task to evaluate change in students' attitudes towards dementia after attending a seminar in which the biopsychosocial model of dementia was taught. Harris and Caporella (2014, 2018) adopted a similar approach when evaluating the effect of being a member of an IG choir, involving university students and people living with dementia, on stigma. Both studies reported high levels of negative words and low levels of positive words at TP1, and large shifts in the focus from negative words to positive. Harris and Caporella (2014, 2018) reported 15% of positive words at TP1, Sabat (2011) reported no positive words. Sabat (2011) found an increase in positive words of 0% to 36.66%, and a decrease of 39.3% in negative words between TP1 and TP2, Harris and Caporella (2014, 2018) found an increase of 63% in positive words, and a decrease of 42% in negative words.

A number of words appeared on the lists more than once, which are outlined in Table 32.

Table 32: *Words which were included in the wordlist more than once*

TP1	**TP2**
Frustration/frustrated (3)	Friendly/friendship (3)
Memory loss/forgetfulness (2)	Memory (2)
Confusion (2)	Confused (2)
Elderly person (2)	Forgetful (2)
Sadness/depression (2)	
Carer (2)	
Brain (2)	
Care home (2)	
Lonely (2)	
Vulnerable (2)	

At TP1 *Frustration/frustrated* appeared on the word lists of three students, other words including: *confusion*, *elderly person*, *frustration,* and *sadness/depression* appeared on the wordlists generated by two students. At TP2, in the current study, *friendly/friendship* was the most common word, which was included on the wordlists generated by three students. These findings support previous studies completed by Harris and Caporella (2014, 2018) and Sabat (2011), who found that the words: *confusion, elderly person, frustration, sadness and depression* featured a number of times in lists generated by students at TP1. Friendship also appeared on the wordlist at TP2 in the Harris and Caporella (2014, 2018), thus suggesting that IG interventions foster friendships.

There were a number of words that featured in both wordlists; *memory, memory impairments, forgetfulness, confused, cared for, supported, elderly, sad, sadness.* This inclusion of words relating to memory loss, and confusion is unsurprising as they are regularly listed as symptoms of dementia (NHS, 2020), and are therefore accurate (Sabat, 2011). It is unsurprising that elderly remained on the list at TP2 as the participants included in the study were all aged 65+. The inclusion of sadness on both lists may refer to the situation/illness or individual characteristics. It is impossible to judge with the limited information provided with one word.

I removed the words that appeared on both lists to assess differences in word themes between the timepoints, to enable more detailed comparisons. Broad themes were identified in both wordlists: Physical, dispositional, emotions, environmental, and needs. The largest change was found in the dispositional category, which are outlined in Table 33. The number of words in this category doubled from six at TP1 to 12 at TP2, and all words in this category at TP2 were neutral or positive. The words: *'unique, an individual'* and *different'* appeared here, which is important as it shows that students recognised the individuality/difference amongst people living with dementia. Recognising the person living with the condition is key to providing good quality person centred care.

Table 33: *Words generated relating to dispositional factors*

Dispositional Words	
TP1	TP2
Personality change	Chatty
Mood	Sociable
Change	Strong
Behavioural change	Coping
Behaviour	Friendly
Vulnerable	Capable
	Enjoys activities
	Big personality
	Creative
	Unique
	Different
	An individual

The number of words relating to the theme of 'emotions', which can be seen in Table 34, at TP1 and TP2 were similar, however the nature of the emotions was different. AT TP1 the emotions listed were all negative, compared to the words generated at TP2 which were all neutral, or positive.

Table 34: *Words generated relating to emotions*

Emotions	
TP1	TP2
Lonely	Happy
Frustrated	Hope
Scared	Joyful
Angry	Emotional
Anxious	

There was a difference in the ‘situational’ words, which is illustrated in Table 35. There was one negative word included in this theme at both timepoints; *isolated* at TP1, and *battle* at TP2. However, a number of positive words were also included at TP2 which painted a picture of a warm, supportive environment.

Table 35: *Words generated relating to situational factors*

Situational Words	
TP1	TP2
Isolated	Battle
	Loving environment
	Friendship
	Community

Table 36 shows a shift in the student perception of the needs of *plwd* was also evident; at TP1 the words suggested significant needs, whereas at TP2 there was only one word here; ‘guidance, which suggests lesser needs.

Table 36: *Words generated relating to the needs of people living with dementia*

Needs of people living with dementia	
TP1	TP2
In need	Guidance
Struggling	
Co-dependent	
Dependency	

Many of the words which appeared in the ‘dispositional’ and ‘situational’ themes appeared to reflect student observations of the intervention, which are characteristic of the findings presented at Chapter 6. For example, students described *plwd* as chatty and sociable after the intervention, during which interaction was found to be a key feature. The findings from the wordlists suggest that students observed participants being able to complete activities, enjoy them, and have fun, and found the *plwd* friendly. The students also described a 'Loving environment'. This suggests that the benefits of providing an intervention which was delivered in a 'loving' environment and addresses the needs of *plwd* underpinned the change in students attitudes too. This concurs with an IG study completed by Lokon, Kunkel and Kinney (2012, p.350) who found that the benefits of maintaining personhood were bidirectional: 'This bidirectional enhancement of personhood in a caring relationship in the 'bridge' that was built across age and cognitive barriers and art was the means for everyone involved in this building project'.

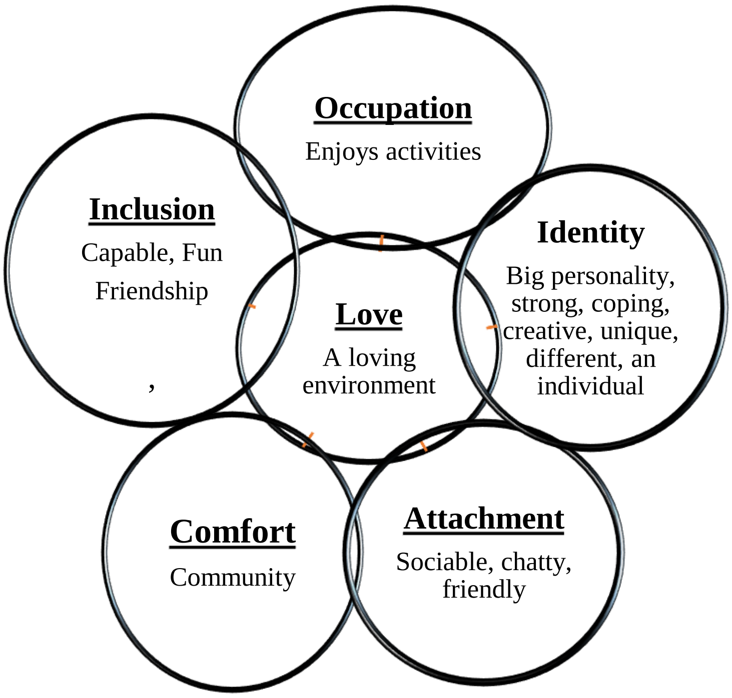

Figure 18*: Words generated by students at TP2 which relate to Kitwood's philosophy of needs*

In sum, the findings from the word task indicated that the intervention influenced students' attitudes towards *plwd* in a number of ways. Students became more aware of individual difference, and personal characteristics amongst *plwd*, and positive emotions experienced in a loving environment.

The study also sought to assess the student experience. Three students attended the IG focus groups where they were asked questions about their experience during the intervention. All of the students spoke; however, their answers were short, and typically expressed agreement with something said by one of the *plwd*. For example, the students agreed with *plwd* 12 who said that they had enjoyed making and eating the fruit salad, that they liked all food, and had enjoyed meeting people. Ppt 13 was the only student that answered the questions directly, before any of the *plwd*.

> Researcher: anything you didn't like
>
> Ppt 13 (student): no
>
> Ppt 14 (student): No
>
> Ppt 15: No, I don't think so

On one occasion I directed a question specifically at the students after the *plwd* had answered the questions and completed their discussion; the aim being to obtain more information from the students. Once again, the answer was short.

> Researcher: girls did you learn anything during the activities?
>
> Ppt 13 (student): How to plant cress
>
> Ppt 14 (student): yea

In sum, direct quotes from the students offered little insight to their experience during the intervention, other than agreeing with the *plwd*, that it was positive. The following section will present the views and opinions of care staff who supported the intervention.

8.2 THE PERSPECTIVE OF CARE HOME STAFF

Two focus groups were completed with care home staff to investigate their experience and address research question three as stated on page 81:

1. *What are the challenges that care homes may face implementing the intervention*?

Each focus group was attended by two care staff who had attended at least two of the activity sessions. To explore the sustainability of this intervention I asked questions about the activities that carers were engaged with now, or had been involved with in the past. Four themes were identified in the quotes: activity provision, key elements of successful interventions, new knowledge and ideas.

8.2.1 Activity provision in the care home

It was clear that activities were important in the care homes. Both groups of carers discussed regular activity provision. The RO staff showed a schedule of activities that they were provided with each month which they could modify to make appropriate for their residents.

> Ppt 7 (carer): each month we get one of these …each day is down each month, some things might be where a lot go downstairs for things, other things ……other things you can do wherever you can do some things on the unit if it's not suitable then we can tweak that and do what would be suitable for our residents so even though that's suggestions it's not like set in stone, so you can go with or change it to suit yourself see?

The IG staff discussed daily activities.

> Researcher: Thank you so first I just wanted to gather a bit of background information so I wonder could I start by asking you about any involvement that you have had with other activities provided here
>
> Ppt 18 (carer): well, we do daily activities is that the thing?

Care staff discussed a varied, and flexible activity provision for residents. RO staff talked about taking residents to a sing-along at the church once a month, which involved an element of reminiscence:

> Ppt 7 (carer): they sometimes go down to (place name removed) for the um…
>
> Ppt 8 (carer): church sing-along once a month, isn't it?
>
> Ppt 7 (carer): yea it's um old time songs

However, most of the activities discussed were arranged within the home, with alternatives provided 'on the unit'. These included activities such as sing-alongs, and carpet bowls, which care staff provided. Activities such as games, concerts, and film nights were delivered in the communal areas and involved all residents, staff, and possibly visitors too.

> Researcher: So, you do it here or, or you take the residents?

> Ppt 8 (carer): we do it in here, yet but like they might have a film night downstairs and they might like have a pub night and if they don't want to go down, we get the with the board games out yer some of them depending how they are might not join in draughts or cards they might do but they might enjoy just watching it could be us playing the games with them helping them along on one isn't it?

Some activities such as pottery, music, and religion were provided by visitors:

> Ppt 18 (carer): we've had a band come, haven't we?
>
> Ppt 17 (carer): yea
>
> Ppt 18 (carer): and everybody is like singing along um we've had um holy communions
>
> Ppt 17 (carer): yea
>
> Ppt 18 (carer): yea
>
> Ppt 17 (carer): we have the reverend coming in once a month

As discussed in Chapter 2 there are many IG interventions delivered in Wales and both care homes had been involved with them. Children, of varying ages had visited the care home from local schools, or playgroups. On some occasions children of school age had sung to residents:

> Ppt 18 (carer): yea we had um the children's choir
>
> Ppt 17 (carer): yes [……]
>
> Ppt 18 (carer): Oh, they were young five six? I would say? [……]

The children's choir had recently visited to sing Christmas songs, which residents had enjoyed.

> Researcher: and they come and sing to the residents?
>
> Ppt 17 (carer): yes, yes were they singing Christmas songs, were they?
>
> Ppt 18 (carer): yea right, I think I know the group that came yea they were um coming up to about 8-year-old

> Researcher: smashing [……]
>
> Ppt 17 (carer): so, um they still come along and sung
>
> Researcher: yes
>
> Ppt 17 (carer): Christmas songs
>
> Ppt 18 (carer): yea uh they everyone really, really, enjoyed

The care staff described other IG interventions in which pre-school children had sung to the residents, which the *plwd* had particularly enjoyed.

> Ppt 17 (carer): They've have also had a group where pre-school have come in as well
>
> Researcher: right
>
> Ppt 17: and interacted and found that the dementia unit residents thoroughly enjoyed that There was a lot of interaction
>
> Researcher: nice
>
> Ppt 17: with the pre-school

During some IG activities the residents had engaged in activities, such as Christmas card making with the residents:

> Ppt 8 (carer): and we did have a group with the children and um the residents making Christmas cards and Christmas decorations

Although the staff were familiar with IG interventions, they suggested that the one-to-one element of the current, '*tea for two*' intervention meant that it was more interactive:

> Ppt 17 (carer): It was more interactive cus it was like a one-on-one basis between
>
> Ppt 18 (carer): yea
>
> Ppt 17 (carer): cus every resident had
>
> Researcher: yea
>
> Ppt 17 (carer): um support

8.2.2 Challenges of activity provision in a care home setting

Few challenges were identified relating to the current intervention in answer to my questions, however, the venue chosen within the care home, and the amount of preparation that was required prior to the first session were discussed. A carer from the IG group suggested that completing the activities in the communal space within the ‘unit’ where participants lived was challenging, due to interruptions which were experienced during the first week of the intervention:

> *Ppt 7 (carer): And I think we had a few interruptions, didn’t we?*

Which distracted one of the *plwd*:

> Ppt 7 (carer) No um I would say only the first session when we were interrupted and and I know with people coming back and fore (name removed) is quite um nosy then shall I say and likes to be a part of everything and was distracted as soon as the door would go somebody come in I know all *their* attention from that turned to that there whoever was coming in

The same member of care staff also highlighted the length of time that the preparations for the first activity session took:

> Ppt7: yes but I think we were a while setting up as well I wasn’t one hundred percent prepared was I although I thought that I was it was still
>
> R: No as you say we it wasn’t you was it as you say there was a lot coming together at one time
>
> Ppt7: yea
>
> R: wasn’t there?

Although care staff considered activities important, they discussed challenges that they experienced providing activities in the care home setting. Staffing levels meant that they were not able to deliver the one-to-one attention that they felt had been responsible for high levels of interaction during this intervention. Levels of staff are recognised in the literature as a barrier to the successful implementation of interventions (Lawrence et al., (2012).

> Ppt 17 (carer):[….] and a colleague alongside um more to as where we would just sit if we were going to do that sort of activity there would probably only be one of us
>
> Researcher: yea for
> sure
>
> Ppt 17 (carer): yea and then sit around the table and go that way so

Because there were two staff watching the current intervention care staff could continue with their caring responsibilities alongside it so I did not disrupt their work activity to any great extent.

> Ppt 8 (carer): because it was relaxed and it was like if we had to go and see someone we just we just did it didn't we you know what I mean we'd go back and fore and we might have to whatever […..]
>
> Ppt 7 (carer): deal with whatever situation and then I think cus it was quite relaxed as well and they're used to us getting up and down we could go off and then just come back in and slot straight back in but as long as there was somebody else here as well so if there was one you know if there was two of us one of us could get up and come back and then the other will just carry on so yea

Demands on the carers time also meant that they needed to think about activities that could be delivered quickly.

> Ppt 8 (carer): and then making us think about things then what we could do because you are busy as carers and we've got to do activities but we do find and they do enjoy sing a longs and we do other things with them

The characteristics of the residents also posed challenges. Carers felt that they needed short activities, which produced quick results, to hold the attention of the *plwd*:

> Ppt 8 (carer): if you're going to do something cus obviously you know at this time it's nothing that's gonna take too long…to see the results coming along

They also needed activities that were likely to appeal to all residents.

> Ppt 8 (carer): the fact that there's a lot of things you could do other things that don't take as long as what you might think but like you said (referring to Ppt 7) it's the attention….and isn't it it's that
>
> Ppt 7 (carer): and it's finding something to grab the attention of everybody
>
> Ppt 8 (carer): mmm

8.2.3 Key factors of successful interventions

The care staff spoke of their own enjoyment of the intervention. The RO care staff said that they had enjoyed seeing the *plwd* enjoying themselves:

> Researcher: that’s good uh as a carer can you tell me about any benefits you felt as a result of being involved with it with the activities?
>
> Ppt 8 (carer): well,
>
> Ppt 7 (carer): I think just knowing that they enjoyed it really
>
> Ppt 8 (carer): mm

This view was shared by carers of the IG group who spoke about the enjoyment that they experienced seeing the *plwd* interacting:

> Ppt 17 (carer): yea really enjoyed it was it was nice to see how they would interact after me telling em in advance that you was coming so they really didn’t know what to expect but that’s
>
> Researcher: um
>
> Ppt 17 (carer): no enjoyed the experience and it was interesting to see I just wish I had seen the last session

One carer discussed the personal excitement they had felt waiting to see if the cress grew:

> Researcher: Did you see them uh watch the cress grow?
>
> Ppt 18 (carer): No, I wasn’t I was on annual leave after that session and
>
> Researcher: oh no problem
>
> Ppt 18 (carer): I was even excited for the cress I said as soon as I came back, I said how did the cress turn out?

Individual personalities were also discussed. Individual characteristics of people involved in interventions is not an area that is explored in the literature, or in this study. Even if this area was well researched, the reality of somehow matching personalities during such an intervention is impractical. However, this is an issue that care staff of the IG intervention identified. They felt that the quiet nature of one of the students was not well matched to one of the *plwd*, who, in their opinion, required the attention of somebody louder to hold their attention.

> Ppt 17 (carer): I would say the student that was with (ppt 11) was very quiet and (ppt 9) and I think *they* needed some somebody to get the attention out

The care home staff felt that the activity facilitator engaged the *plwd* because she was loud.

> Ppt 17 (carer): Um I felt they were timid so the residents came uh that come across with the residents as well so then so I think if they were more I know your facilitator she was when she moved to the top of the table made a difference
>
> Researcher: Right
>
> Ppt 17 (carer): When on the first session to when she was sitting in the group
>
> Researcher: yea
>
> Ppt 17 (carer): um you need to be I feel a bit loud and
>
> Researcher: yea
>
> Ppt 17 (carer): To get their attention in
>
> Researcher: so, you felt the facilitator did that
>
> Ppt 17 (carer): yes

8.2.4 Ideas for change

As a result of their involvement with the intervention care staff discussed some new ideas; to improve the intervention, to deliver new activities, and to change some of the ways that they delivered care.

Care home staff provided suggestions as to how to improve the intervention. Some of these were voiced during the intervention and could therefore be actioned during the intervention. Others were voiced during the focus groups, after the intervention was completed therefore were ideas for the future.

RO care staff suggested that the introductions/instructions at the beginning of the session were shortened and that reminiscence was incorporated with the activity as opposed to before it.

> Researcher: good thank you can you tell me anything that you didn't like about the activities?
>
> Ppt 7 (carer): a bit only like a get straight into it rather than sort of
>
> Ppt 8 (carer): mmm
>
> Ppt 7 (carer): reminisce about it speak about the reminiscence while you're doing it the practical was fine wasn't it?
>
> Ppt 8 (carer): yea

These changes were actioned during the intervention, which care staff felt made a difference to the experience of *plwd*:

> Ppt 8 (carer): cus that's what we done the last couple of times where you were sort of like obviously you were going to say what we're going to do
>
> Researcher: yea
>
> Ppt 8 (carer): and whatever but there we were like talking about things where you changed it then where you tell em what you're going to do and you'd be talking while you do it
>
> Ppt 7 (carer): while you do it and
>
> Ppt 8 (carer): and that went down
>
> Ppt 8 (carer): much better
>
> Researcher: yea
>
> Ppt 8 (carer): I think that went down really well

After the intervention (during the focus group) the care staff also suggested that a bit of background music would improve the intervention:

> Ppt 8 (carer): As an afterthought as well even though I know the telly is on now we've always got a bit of music on as they tend to enjoy the music it's if you were somewhere where maybe you were going in and it's just like well this is our area to have a little bit of quiet music in the background it always seems to
>
> Ppt 7 (carer): relax
>
> Ppt 8 (carer): relax them
>
> Ppt 7 (carer): all our other residents don't get
>
> Ppt 8 (carer): you know just to

> Ppt 7 (carer): into television programmes bit but they can they will sit with their feet tapping or their hand clapping on the table
>
> Ppt 8 (carer): yea

IG care staff suggested a chance for the students and *plwd* to meet before the intervention would be beneficial to help overcome nerves:

> Ppt 17 (carer): Um only what I touched on earlier if the group were more um not so timid then
>
> Ppt 18 (carer): Yea
>
> Ppt 17 (carer): in a little bit
>
> Ppt 18 (carer): Maybe if they got to know to know the person just a little for about 10 minutes before have a little chat and um
>
> Ppt 17 (carer): they did um
>
> Ppt 18 (carer): maybe

And implicitly suggested that louder students would be beneficial for *plwd*.

> Ppt 17 (carer): Um I think maybe personally um I know the students were very nervous as well um but if they were a little bit more vocal and a little bit louder speaking I am quite loud anyway myself
>
> Researcher: and I am
>
> Ppt 17 (carer): Um I felt they were timid so the residents came uh that come across with the residents as well so then so I think if they were more

Ideas to use the intervention:I asked all focus group participants whether they had learned anything during the intervention. Some of the carers had not tried some of the activities before, such as planting seeds on kitchen towels.

> Ppt 7 (carer): I never dreamed of that um I wouldn't ever and to be honest I wouldn't have known how to do the mustard seeds and that I wouldn't have thought of growing mustard seeds and that
>
> Ppt 8 (carer): ah I've done it with the kids at home
>
> Ppt 7 (carer): it's new to me

Or making ice-cream with evaporated milk:

> Researcher: nor me only I I looked it up *laughter*

> Ppt 7 (carer): yea it wasn't something that I would have known I have only ever planted in in a I've never done it on paper and I don't know I didn't know that you could make ice cream you know from Carnation milk

Care staff from the RO group said that they might use the ideas for ice-cream, and fruit salad again, plus they considered some options involving food, from their previous experience:

> Ppt 8 (carer): we do things daily anyway but we might do something like the physical doing the fruit salad the ice cream like I said maybe we'll do the salty dough Christmas
>
> Ppt 7 (carer): yea
>
> Ppt 8 (carer): we can do it in the microwave so it doesn't take it doesn't take long to dry out so they're not not waiting 3 or 4 or overnight for things to dry out which is something that can
>
> Ppt 7 (carer): I think the fruit salad
>
> Ppt 8 (carer): be done within the day
>
> Ppt 7 (carer): is quite nice we could do that in an afternoon
>
> Ppt 8 (carer): we'd enjoy that
>
> Ppt 7 (carer): and they could have that for their pudding, couldn't they?
>
> Ppt 8 (carer): yea
>
> Ppt 7 (carer): for tea time so that's something that would be nice to do

One of the IG carers (ppt 17) said that they would not use the ice-cream again:

> Researcher: ok um so how likely are you to repeat uh is there anything in these activities that you think might you might repeat? Or anything
>
> Ppt 17 (carer): I don't think we would do the ice cream

Ideas for standard care: Ppt 17 said that they had not learned anything about the *plwd* as they had known them some time, and knew how they would react to the intervention:

> Ppt 17 (carer): only the only thing I would say not to ignore your question is cus we know the residents really well it's hard to say
>
> Researcher: for sure

> Ppt 17 (carer): Do you know what I mean um like I knew that (Ppt 10) and (ppt 12) would be quite independent I knew which way they were going to react if you know what I mean
>
> Researcher: yea yea
>
> Ppt 17 (carer): Before so it's hard to say that I learned something um
>
> Researcher: yea
>
> Ppt 17 (carer): cus I work with them that you know

They also knew who would decline:

> Ppt 17 (carer): yea see I already know the residents
>
> Researcher: yes yes you knew when I didn't
>
> Ppt 17 (carer): I knew exactly who would have declined

Interestingly, later on in the focus group they said that they had been surprised by the ability that ppts 10 and 12 had shown when making the sandwiches:

> Ppt 17 (carer): yea I didn't think their skills were gonna be as great with a knife but
>
> Researcher: yea
>
> Ppt 17 (carer): mm
>
> Researcher: that's interesting

This is important as it prompted the member of care home staff to consider involving the participants in preparing some of their own food. Not allowing *plwd* to use the abilities that they do have would be disempowerment according to Kitwod which will lead to illbeing (University of Bradford, 2016, p.38). The care staff of both groups suggested that they could involve *plwd* in the preparation of their own food. The RO carers suggested that *plwd* could become involved in making fruit salad for afternoon tea:

> Ppt 8 (carer): as ppt5 said it was wouldn't it be nice if you're having fruit salad that the residents on each unit made their own for dinner and it's then if you don't like it you don't need to have oranges or if somebody does you can have that

The IG carers suggested that *plwd* could become involved in making their own sandwiches:

> Ppt 17(carer): I do think with ppt 10 and ppt 12 we could, watching them their skills with the knife when they were chopping up the fruit for the salad we could be be giving them some more things to do we tend to take that bit away where they could be making maybe a sandwich I don't know how they made their sandwiches on the end session
>
> Researcher: good
>
> Ppt 18 (carer): really good yea
>
> Ppt 17 (carer): whereas we tend to say if they think they will have a sandwich for tea we make it
>
> Ppt 18 (carer): yea
>
> Ppt 17 (carer): so why not?
>
> Ppt 18 (carer): yea so give em a little bit more independence in making their own
>
> Ppt 17 (carer): yea
>
> Ppt 18 (carer): bits and bobs

Care staff of both groups felt that they could provide participants with the opportunity to become more engaged with preparing their own food. Staff stated that they currently make sandwiches for *plwd* and if fruit salad is on the menu it is prepared in the kitchen and brought to 'the unit'. During the intervention care staff observed *plwd* becoming involved in these tasks themselves, choosing what fruit that they wanted to include in their fruit salad and buttering the bread and choosing the contents of their sandwiches. Care staff suggested that they could provide *plwd* with the opportunity of doing this on a regular basis. Lawrence et al. (2012) found that interventions appeared to prompt the staff to examine their actions when caring for individuals.

The Welsh Dementia Action Plan (Welsh Government, 2018) includes a commitment to provide meaningful care in care homes, which addresses the emotional and social requirements of the individual. Involving residents in the preparation of their own food would also address some concerns of the OPCW (2014) who found that the care home environment is often lacking in meaningful activity such as making tea, baking, and gardening.

8.3 CHAPTER SUMMARY

The findings reported in this chapter suggest that the IG intervention has the potential to improve the 'dementia knowledge' and attitudes of university students towards people living with dementia. Students' attitudes appeared to change as a result of the intervention which did not hold pose many challenges for care home staff. Care staff felt that the intervention had a number of key elements, in essence it had addressed a number of the challenges that they faced when providing activities, such as staffing levels, and finding activities that are quick and easy to deliver, however the amount of preparation involved prior to the first activity session of the IG intervention was discussed. A number of suggestions were made to improve the current intervention such as including background music which could be incorporated to suit individual tastes in different care homes. The intervention prompted care staff to consider other food-based activities, and involving *plwd* in preparing some of their own food.

9 CHAPTER 9: DISCUSSION AND CONCLUSION

The thesis set out to undertake an original and ambitious project, not only through its design, but also by identifying 4 research projects, which required observation of complex individual human behaviour and norms, in a context of care practice. Together, these questions sought to identify new knowledge about the effectiveness of the intervention in enhancing wellbeing for *plwd*; its potential to improve knowledge and attitudes about dementia amongst young adults; the challenges implementing the intervention may represent; and finally, its potential to inform care delivery in a residential home context.

The questions therefore encompass considerations of complex socio-cultural factors about individual behaviour and norms as experienced by three distinct groups of individuals – older people living with or without dementia, their paid carers, and a future cohort of young people who will themselves, shape how society embraces dementia or not into the future. All these factors were assessed in a care environment, which all too often, remains remote from its wider immediate community context. Fundamentally, the research aimed to change care practices and attitudes towards dementia, and enhance wellbeing by improving communication and contact between *plwd*, their carers' and a select number of younger people, as they interacted in a communal setting, the care home. Recognising the complexity of these aims, the research adopted a complex, mixed-methods experimental framework, which involved the collection of qualitative and quantitative data from residents and care staff in two care homes, and university students from the community.

The remainder of this chapter consists of reflections on; 1) key findings, 2) the theoretical framework which informed the design of the intervention, and interpretation of the results; 3) the methodology used to complete the study; and 4) the implementation process which will outline the challenges faced undertaking the research, how these were addressed, and lessons learned, to assist future researchers who may be planning similar research. This chapter will conclude by considering the potential for future research in this area.

9.1 KEY FINDINGS

In sum, the findings for each of the research questions outlined in detail in previous chapters were that:

1: The intervention did enhance the wellbeing of *plwd* notably through their high levels of attendance during the intervention, the amount of time they spent in positive well-being, and the increase experienced in average mood and engagement amongst the IG group during the individual activity sessions (see Chapter 6 and sections 2 and 3 in particular).

2. The intervention did improve students' overall attitudes, knowledge about, and comfort level towards *plwd*, as demonstrated through an increased awareness of individual difference, and personal characteristics amongst *plwd*, and positive emotions experienced by people living with the condition (see Chapter 8 and section 1 in particular).

3: Very few challenges were experienced in implementing the intervention, the main issue discussed by care staff (see Chapter 9 and sections 2 in particular) was their inability to provide the one-to-one element that was considered invaluable.

4: Care staff themselves recognised the potential for the intervention to improve care delivery by building on the abilities participants had demonstrated during the intervention (for example involving *plwd* in preparation of their own sandwiches in Chapter 9, section 2), and as a result, enhance their wellbeing.

The findings from this study, which was essentially a proof-of-concept exercise, suggest that the intervention is practical for the care home environment, and acceptable, generally engaging, and safe for participants. It is hoped that the findings of this study will be useful to individuals who are considering similar interventions in the future.

9.2 THEORETICAL REFLECTIONS

9.2.1 How the findings support the theories of Kitwood and Allport

Findings from this study support Kitwood's model of care (1997a, 1997b), and contact theory (Allport, 1954, Pettigrew 1998). The provision of a supportive environment in which *plwd* and students were treated as equals, felt comfortable (see Chapter 7 section 1), formed friendships (see Chapter 7 section 2.6), and prepared food and ate together which both groups enjoyed, resulted in wellbeing for *plwd*, and greater comfort with, and knowledge of *plwd*, amongst students.

Findings from the qualitative data in particular (see Chapter 8) support Kitwood's philosophy of care (1997) which suggests that meeting the needs of *plwd* in five areas is crucial for maintaining personhood; attachment, occupation, inclusion, identity, and comfort, all of which equate to 'love' and will have a positive effect on wellbeing. Specifically, the intervention was shown to have met all 5 of these needs in the following ways: introducing students to the care home environment in a purely social capacity resulted in high levels of interaction and evidence of friendships formed. Offering *plwd* the opportunity to engage in preparing food with a partner provided meaningful occupation, and *plwd's* reactions were generally ones of enjoyment and willingness to engage, a behaviour also noted by care staff. Providing a flexible intervention that *plwd* could engage in to the extent that they found comfortable, by watching, interacting with others, and/or completing the activities, resulted in a relaxed experience. Providing *plwd* with the opportunity to express elements of their identity by reminiscing resulted in enjoyment, and delivering the intervention in the home of *plwd*, supported by residents and care staff that they were familiar with enabled them to relax. As Kitwood (1997) states, meeting these 5 needs resulted in relative wellbeing IB for *plwd*, on the few occasions where the needs of the *plwd* were not met, this resulted in illbeing.

An original finding from the research was the importance of choice, an important factor highlighted during the focus groups (see Chapter 7, section 1). The notion of choice did not appear to relate to any of the needs identified by Kitwood, but can be aligned with the need for individuals to be able to exercise agency, as suggested by Kaufmann and Engel (2014). In their study examining Kitwood's model of psychological needs and wellbeing Kaufmann and Engel (2014) found three components; self-determination, freedom of action, and independence, which they could not assign to any of the 5 needs; they therefore suggested that Kitwood's philosophy should be extended to include a sixth need entitled Agency. The findings of this thesis support such an extension.

In sum, the findings of this thesis supported Kitwood's theories which capture the essence of wellbeing, with the addition of Agency as a need.

Contact theory (Allport, 1954, Pettigrew, 1998) was also found to be effective for designing an IG intervention aimed at improving attitudes towards 'outgroups' in this case older *plwd*, essentially because students were able to perceive *plwd* as individuals, rather than simply 'people living with dementia'. Furthermore, findings from the intervention also show that the criteria of contact theory (Allport, 1954) have been met. The challenges of meeting these in an IG intervention involving plwd and students, in a care home context are discussed in section 9.2.2.2 (pg.218). All participants were treated as equals when preparing the food and enjoying it together, and this represented shared goals; the intervention was delivered for approximately an hour a week over four weeks which was found sufficient for friendships to form; and the care home staff and research team provided a supportive, normative environment. 'Outcomes' for students were assessed post intervention, when quite a striking increase in students' knowledge of, and comfort with, dementia was found. Pettigrew's (1998, p.80) addition to the contact theory: 'the contact situation must have friendship potential*'* was found to be the factor that enabled it all to happen, as the friendships made appeared to be a key element that brought about the change.

Relationship is a key theme in both theories which complement each other for IG interventions This is consistent with findings from previous studies. George (2011) found relationship building to be a key mechanism underpinning change in a study which found that IG volunteering improved the QOL of *plwd.* Lokon et al (2017) suggested that relationship building was at the foundation of the change in comfort with, and attitudes towards *plwd* amongst students after their involvement in an IG arts project.

Factors which enabled the relationship between *plwd* and students in the current study were: time, a supportive environment for both groups where all participants are treated equally, and a collaborative task that both groups enjoyed. Lokon et al., (2017) highlighted the importance of having a common focus or task as a basis for IG interventions aimed at improving students' attitudes towards *plwd*. Allport (1954) and Pettigrew (1998) did not stipulate that the common goal should be enjoyable, so perhaps this is something particular to IG interventions.

In sum, the findings of this thesis support contact theory (Allport 1954, Pettigrew, 1998) which outlines optimum conditions which bring about an increase in students' comfort with, and attitudes towards *plwd*.

9.2.2 Critical Reflections on the theories of Kitwood and Allport

Whilst findings from this study offer support for the aspects of Kitwood's model of care (1997a, 1997b), and Allport's contact theory (Allport, 1954, Pettigrew 1998), as discussed above, the findings also raise questions about them. This section will offer critical reflections about the questions my own findings raise in terms of Kitwood and Allport's theories, whether my findings resonate with other theories to provide a broader interpretive framework for the study of *plwd,* and what unique contributions my research has made to existing knowledge in the field of *plwd* in a residential setting.

9.2.2.1 Critical reflections on Kitwood's theories

My findings raise questions about Kitwood's theory, notably in terms of its omission of certain aspects relating to the notion of need. I reflect on my findings in relation to the work of Kaufman and Engel (2014) who have also offered critical evaluations of Kitwood's initial framework.

Kaufman and Engel (2014) extended Kitwood's initial framework in two ways, by recognising people's attachment to animals, tasks, and 'anchor items', that is items which mean something to the person; and by acknowledging agency and its components of self-determination, freedom of action, and independence. My own research also illustrated the importance of recognising attachment to tasks. Participants two and twelve had exhibited attachment to the task of gardening, one by speaking about their gardening experience, the other by showing the research team flowers that they had grown in the care home garden. Both experienced positive wellbeing during the indoor gardening session, when planting the cress and mustard seeds. My findings therefore illustrate the paucity of an overarching concept of attachment, as outlined by Kitwood (1997).

My findings also corroborate with Kaufmann and Engel's (2014) identification of a need for individuals to exercise agency, a factor which Kitwood had not identified. A need for self-determination was exhibited by participant three who had limited verbal communication skills however could still exercise agency very effectively by pushing away the feedback sheet which I handed out at the end of each activity session. This was a clear signal that they did not want to complete it. A need for self-determination was also evident as participants enjoyed the choice that the intervention offered. During the focus groups the care home staff stated that participants had enjoyed choosing which fruit to put into the fruit salad which corroborated this finding.

However, in addition, my findings provide a unique insight into one other dimension of need, by showing the importance of attachment to people external to the residential environment in which they lived. This was clearly illustrated during the intervention when *plwd* particularly enjoyed the company of the students, that is people other than those living in the care home. The DCM results testified to this (see chapter 6, p. 148-153) with wellbeing scores increasing for some residents, for example when they saw the students arriving for the intervention and when they engaged directly in conversation with them.

The rationale for bringing the students into the care home setting was to challenge the problem of social isolation amongst care home residents, particularly residents living with dementia in the institutional setting. Goffman, back in 1961, drew attention to the alienating effect that institutional life would have on older people, creating a level of 'separateness' and social isolation. Others have highlighted the importance of an attachment to the external environment in the wellbeing of *plwd*. In a meta-synthesis of studies exploring Qol amongst *plwd*, O'Rourke (2015) identified connectedness to external surroundings as a critical concept essential to wellbeing. These researchers and my own findings point to the importance of extending Kitwood's notion of need for attachment to incorporate the idea of attachment to the external environment.

In sum, my findings corroborate with those of Kauffman and Engel (2014), and extend both theirs and Kitwood's concept of attachment further to include recognition of a need to attach to people from the external environment, from where they live.

9.2.2.2 Critical reflections on Allport's contact theory

Contact theory underpinned the design of the research intervention aimed at bringing about positive interactions between the groups and a change in attitudes of students towards people living with dementia; it was not used to assess any change in the attitudes of *plwd* towards students. The following section will discuss the challenges, and appropriateness of the use of each of the tenets of contact theory (Allport, 1954) and the additional tenet subsequently suggested by Pettigrew (1998), in a care home context.

Equal status

Equal status may be challenging to achieve in a contact situation within a care home context as residents living with dementia have been found to experience low status (Clare et al, 2008, Steele et al, 2020). In an aim to achieve equal status between the groups all participants were addressed by their first name, care home staff and the research team supported all participants, and both groups were working together during the tasks, neither group was instructing the other. Whilst we do not know whether *plwd* felt equal status, as I did not ask any questions about this, the findings suggest that they did because the *plwd* generally experienced the intervention as positive (page 162). Furthermore, there are some examples of *plwd* shaping these interactions, for example Ppt 12 sought to understand what the students liked to drink; and another Ppt 11 showed agency by attending the first two sessions and choosing not to join after that. Whilst it can be argued that students encouraged and assisted the *plwd* to complete some tasks, the *plwd* also supported the students. For example, Ppt 12 encouraged students to engage in the conversation during the focus group, this is shown when they added 'didn't we?' to the end of their response to one of my questions and the students agreed with what she was saying (see pg 152).

Common Goals

My research questions did not focus specifically on the importance of common goals, and it is not possible to state with any certainty that all of the *plwd* were able to perceive the activities in the intervention around preparing and sharing food as a 'common' goal. The initial assessments which were completed for *plwd* participating in the study using the PAL occupational profile (see page 124), showed that one participant had a 'Planned' profile which suggests that they were able to engage in activities with an end goal and a set process or recipe. The other three participants were assessed as having an 'exploratory' or 'mixed' occupational profile which suggests that they were able to complete complex tasks if broken down into steps and demonstrated, but may not appreciate the end goal. Nevertheless, the *plwd* and students engaged collaboratively in the tasks which made up the overarching goal, therefore could be considered as smaller goals. The results indicated that the *plwd* experienced the intervention as positive, and the students' attitudes towards *plwd* improved, which may indicate that the perception of shared goals is not required to effect positive interactions between the groups, or that much smaller 'common' goals are sufficient to engender positive interactions in these two groups of participants.

Notwithstanding this, my findings point to the relevance of the factor or "common goals" as something which, through a shared activity, can enhance wellbeing. The activity of preparing and sharing food led to relationship building between the groups. I observed many examples of students, and residents living with dementia, developing relationships over the activities, for example Ppt 9 experienced positive wellbeing while mixing the ice-cream mixture and engaging with one of the students.

A supportive environment sanctioned by the community

Allport (1954, p.281) highlighted 'institutional support' as a key tenet in contact theory required for attitude change, stating that: 'the effect is greatly enhanced if this contact is sanctioned by institutional supports'' (i.e., by law, custom or local atmosphere). This tenet was considered: 'an especially important condition for facilitating positive contact effects by Pettigrew & Tropp 2006, p.766). The current intervention was supported by area and care home management teams and staff, and by the university, which satisfies the conceptualisation of 'institutional support' generally discussed in the contact literature, which is the support of the organisations directly involved in the intervention, however Allport's reference to 'law, custom, or local atmosphere' may also be conceptualised to encompass peers, family, and the wider community (Loader, Hughes and Furey, 2020). Support for such IG interventions may not currently be universal.

Although there is an increasing focus on IP and IG interventions in care homes in Wales, which is discussed more fully in Chapter 2, section 4 and Chapter 9 section 4 they are not currently ingrained into the fabric of society, in other words are not ‘the custom’ as Allport (1954) suggested. The care home setting is unlike the ‘norms’ of society, as care home residents spend most of their time socialising with the other older residents, and have diminished contact with the outside world. Students may not typically enter a care home environment unless they work there or have loved ones living there, who they visit. Whilst countries such as Denmark have university students living in care homes for older adults (The Conversation, 2016), this is not the norm in Wales at this time. Nevertheless, the study found an increase in positive attitudes towards dementia amongst the students, and was generally enjoyed by the *plwd*. This may suggest that inconsistent levels of ‘institutional support’ from the wider community may be sufficient to reduce stereotypes and bring about a change in attitudes. However, as IG interventions become more commonplace this should result in more wide reaching, significant and sustainable improvements for both participant groups, according to Allport (1954); in essence, as ‘institutional support’ from the wider community increases, such interventions should become more effective. In a study which explored shared education as contact programmes in schools in Northern Ireland and North Macedonia Loader, Hughes and Furey (2020, p160) found that the most effective programmes were delivered in areas in which the ‘wider educational and political systems’ demonstrated support for the programmes.

Building Relationship (True acquaintance/Friendship)

Neither Kitwood (1997) or Pettigrew (1998) stipulated the length of contact required to develop the relationships that they outlined; however, some Intergenerational interventions have reported improvement in attitudes towards *plwd* in short interventions. Intergenerational studies ranging from an hour-long poetry session (Garrie et al, 2016) to two 20-minute contact sessions for a year (Camp et al, 2004) have found improvements in students’ attitudes towards *plwd*, suggesting that friendly, supportive, interactions, sufficient in depth to bring about change, can happen quickly.

There is evidence in my study of friendships developing over time. For example, participant 10 and participant 12 asked whether anyone was coming back after the first week. The relations which developed between the groups were important for the students too. ‘friendly/friendship’ was the most common word, used by students on the wordlists that they produced after they had completed the intervention. This word was not included in the student wordlists which they prepared before joining the intervention, which suggests that the students experienced friendship during the intervention. This was likely to play a part in the increase in positive attitudes towards people with dementia which resulted. During the current study many positive interactions were observed between the participants, and an improvement in attitudes towards dementia amongst the students was found, which suggests that the length of the intervention (an hour-long activity once a week for four weeks) is sufficient to satisfy this tenet of Allport’s theory.

To conclude, overall, my findings do justify the relevance of using Allport and Pettigrew’s factors of contact theory to form the basis of intergenerational interventions in care homes involving *plwd* and students, and assess the effectiveness of an intergenerational intervention focusing on food in the care home context as a way of reducing stigma/stereotyping. The findings point to the importance of treating participants equally, sharing tasks, developing relationships in this context, and providing a supportive organisational environment but question whether support from the wider community is necessary to result in positive interactions, and a change in attitudes. From an applied perspective use of contact theory as an important tool in facilitating positive intergenerational contact.

9.2.3 How findings resonate with other theories – citizenship and embodied personhood

Whilst I found support for Kitwood’s framework of psychological needs (see Chapter 7), viewing the findings through a citizenship lens has highlighted the narrowness of his original conceptualisation of need as attachment, occupation, identity, inclusion, and comfort.

Drawing on Bartlett and O’Connor’s (2010) citizenship-focused framework (see Chapter 3, section 5), my own findings take on a new meaning when considered in terms of concepts of *solidarity* and *purpose*. For example, as a manifestation of solidarity, when a participant felt unwell during the IG intervention, other residents intervened by encouraging them to stand so that care home staff could help her to her room. Similarly, one of the participants in the RO intervention helped another by smoothing down their apron when they started to prepare food.

The notion of *purpose* (as opposed to occupation) also adds a new interpretive perspective to my findings. For example, more than just being an "occupation", one participant found meaning and pleasure in being the person who often helped around the unit by wiping the kitchen tops down, and clearing up after the activities. The same can be said of the participants' investment in preparing and eating food. This sense of enjoyment or purpose was expressed during the focus groups by participants and was observed by care staff (see Chapter 7, p. 152).

In sum the citizenship perspective has helped highlight potential new paradigms for interpreting residential living, food and *plwd*. In essence the broader concepts of solidarity and purpose as opposed to attachment and occupation were found to be worthy of further consideration and exploration. They point to the need to recognise self-initiated agency amongst *plwd*, a group very often assumed to lack both, notably in a residential care setting.

My findings also found support for the theory of embodied personhood as suggested by Kontos (2004). As discussed in Chapter 2 section 5, a key premise of embodied personhood is that agency can be expressed through the body. Kontos (2004) suggests that *plwd* are able to maintain their agency and personhood using bodily movement, a type of language that is unaffected by the cognitive decline experienced by *plwd*. I observed a number of instances of embodied personhood displayed during my study. For example, one participant whose verbal communication skills were limited used gestural communication (Kontos, 2004) by turning their head away from another speaker when they did not want to engage, and winking when they were enjoying themselves. These gestures of awareness and sensitivity towards others align with Kontos' (2004) recognition of 'caring'.

When interpreted using the explanatory lens of "embodied personhood", some of my findings clearly suggest that people living with dementia *are* able to retain their personhood and agency, a direct challenge of Kitwood's claim that other people are required so that a *plwd* may maintain their personhood. His stance on this overlooks any notion of individual autonomy for *plwd*.

In sum, whilst on a basic level, Kitwood's framework is valid, my research, along with that of others, illustrates a more complex and nuanced picture which situates the individual in relation to others and to the immediate physical and broader societal structures to which they belong. Kitwood's theories were innovative at the time, and have been very influential in the field of dementia care. He advocated treating *plwd* as people who matter, a claim which continues to be valid as societies persist in seeing them as "other". Theories of citizenship and embodied personhood show potential to extend his basic notions of personhood further, by introducing an understanding of *plwd* as those with agency, as well as awareness and sensitivity towards others.

9.3 STRENGTHS AND LIMITATIONS OF THE STUDY

This section will focus on the strengths and limitations of the study; it will include reflections on the challenges and lessons learned during intervention design and implementation, and challenges of the methodology, study size, and participant demographics.

9.3.1 Reflections On the Implementation and Lessons Learned

The study was challenging to implement, as found by others who have completed similar studies involving IG interventions with *plwd* in a care home setting. (DiBona, 2017, Jarrott & Bruno, 2003, 2007, Kirkland et al. ,2014). Although the intervention was completed safely within agreed timeframes, generally enjoyed by *plwd* and created few issues for the staff, it nonetheless required 'skilled preparation and facilitation' by researcher, and research team' *(DiBona, 2017,* p11). for example, the researcher recruited and transported students to the site.

Good planning, the appointment of an O/T, the use of the PAL checklist (2012), and strong collaboration with the care home staff resulted in activities that were well accepted by *plwd* who were able to engage with them. This was highlighted in the focus groups (see Chapter 7, section 2). The appointment of an activity facilitator meant that the delivery of the intervention was consistent across both sites, and

‘Sessions appeared mostly well planned and facilitated’ which is also consistent with DiBona, (2017, p.11). The enthusiasm of the facilitator was mentioned by care staff as a positive during the focus groups (see Chapter 8, section 2). The intervention was flexible and changes could be made during implementation; (see Chapter 7, section 1).

9.3.1.1 The complexity of designing and undertaking an IP study

IP has traditionally been a multidisciplinary field, requiring different groups to interact and collaborate together. Typically, this means laypersons (for example, *plwd* and their families), volunteers, charities, state and private service provider organisation, funding bodies and the research community will be called on as part of the design and delivery of IPs (Vieira and Sousa 2016, p.408). Whilst providing a rich mix of expertise, knowledge and skills, such teams may by nature, be challenging to manage on several fronts. Adopting an IP design for this research therefore meant recognising and managing such complexities from the outset.

The first challenge is to recognise that time is of the essence. It took a long time to establish and build a multidisciplinary team. In the early stages the team grew from myself and my supervisor to include care home board members, an activities facilitator, and an O/T, who were recruited through contacts within Swansea University and their external contacts within Health and Social care organisations. As the project progressed, care home managers, staff (care and kitchen staff), residents and their families, and students were recruited to the project. This process involved gaining appropriate permissions from the organisations involved so that I could contact the relevant individual and invite them to join the project. For example, permission had to be gained from the University to appoint the O/T as an honorary member of staff for the duration of the programme. The contacts made through the University and supervisory team were key to the success of the project.

The recruitment process required me to gain access to participants from different locations, and to formally integrate others into the research process, a step in the research which is time consuming and therefore requires extensive planning, time management and good interpersonal skills.

Another challenge was developing the scheduling and coordination of activities across the different bodies involved (see Appendix 27). The timing of the intervention was dictated by a number of factors which were largely beyond my control, primarily the care home operation. The day and time (Monday and Wednesday at 3) were identified by the care home managers as optimum for the care home staff and residents. Once this was agreed these timings had to be coordinated with the activities facilitator and students who were volunteering for the project, all of whom had various work, study and holiday commitments. There were also some challenges negotiating a 4-week window for the intervention, as the care homes had activities already scheduled. This process required some flexibility and collaboration between all parties, yet despite this some last-minute changes were also required due to double bookings at the care home.

The timing of participant recruitment was also challenging, because as this was an IP programme both groups of participants had to be recruited simultaneously. In my research plan I had scheduled the month prior to the intervention delivery to recruit care home staff and residents as participants. I visited the care homes once a week for the month to meet staff, residents, and families to discuss the project and gain informed consent from potential participants. The care home managers had agreed to act as gatekeepers, therefore they needed to contact families of participants who required additional consent to participate. This process was dependent on the time available to the care home manager, and the visiting schedule of family members. In practice some care home residents were recruited several weeks before the programme started. I recruited and gained informed consent from two residents approximately two weeks before the intervention was due to start who decided later that they did not want to participate. There is no way of knowing why these participants changed their mind, but the care home manager thought that this was because they had been recruited too early. The timing of student recruitment had to coincide with this, in a timely manner. The manager of Studentzone at Swansea university suggested that I recruit very close to the start of the project, which I did. However, this took longer than anticipated. At one point I was worried that I would have to attempt to reschedule the intervention due to a lack of student participants.

Other logistical issues included the transportation of students to and from the care home, and illness. One *plwd* experienced illness during each intervention, and one student during the IG intervention, which meant that they were unable to attend all four sessions. One way to overcome this would be to recruit more participants for each group than planned, to cover such eventualities. However, challenges were experienced recruiting four participants that were in the research plan, in each participant group; residents, residents living with dementia, and students, therefore this may be challenging.

9.3.1.2 Challenges of doing research in a care home environment

The care home environment is a challenging one in which to implement and assess an intervention, as staff are busy, other people not involved in the research such as other residents, care staff and visitors are occasionally present which may affect the *plwd* mood, engagement, and behaviour (Kirkland et al., 2014). There were numerous factors to consider when scheduling the intervention and data gathering; care homes schedules, staffing levels, availability of the activity facilitator, and students. Prior preparation and strong collaboration with the care home staff were key to addressing these issues, as found in previous studies (DiBona et al, (2017, Wood et al., 2017). As discussed in Chapter 6, I completed a great deal of prior preparation, visiting the care homes on numerous occasions before the intervention began, building relationships with care staff and residents, and introducing the activity facilitator. Despite rigorous planning, unexpected events occurred once the intervention had begun which meant that the schedules were affected. For example. the care home asked us to reschedule one of the weekly sessions for operational reasons, and work schedules meant that the focus group for the IG intervention was slightly later than planned, and involved two care staff rather than the three that had supported the intervention. The relationships built between care staff and the research team resulted in a strong collaboration which meant that all parties worked together to decide on strategies that were workable for all. Another challenge was that a number of the students had no transport; as the study was small, the activity facilitator and I could transport them but this is something that requires consideration in similar studies.

Good planning and strong collaboration meant that these issues could be addressed with minimum disruption however there is no way to eradicate them from similar studies. Researchers need to plan well, build good relationships, build flexibility into the schedule, and be approachable, adaptable and resourceful.

9.3.1.3 Challenges encountered during Intervention implementation

There were some factors that did not go as planned, for example the ice-cream did not set as hoped, which was disappointing but did not appear to impact the experience of *plwd* significantly; the ice-cream was eaten a little runny. The cress that was grown during the intervention was a little yellow therefore we replaced it with freshly grown cress to include in the sandwiches. Some participants stated during the intervention that they did not like eggs therefore we added ham and cheese as options for the sandwiches. In my draft plans for the research, I intended the care staff to simply observe and support as required; however due to low numbers during week 1 of the Residential Only intervention staff took the place that I had planned for residents and paired up with *plwd* during the activities. This again illustrates the importance of flexibility and collaboration with the care home staff.

9.3.2 Reflections on the Methodology and lessons learned

The Mixed Methods research design was good. A pragmatic MM research design was adopted to complete the study, the rationale for adopting this methodology was discussed fully in Chapter 3; briefly, this approach enabled the researcher to explore the experience of the intervention from the perspectives of three groups of participants; *plwd*, students, and care home staff (Creswell & Creswell, 2018), through the collection, and integration of quantitative and qualitative data (Creswell & Plano Clark, 2018). A mixed methods approach in research involving *plwd* is endorsed by Brooker (2019) who suggests that *plwd* can report on their own experience and posits that: ‘a combination of observations and interviews may offer the most comprehensive and inclusive approach’ (p.80). This method was effective in gathering a variety of data from multiple perspectives, and the strengths of one method ameliorated the limitations of others, therefore providing a more accurate, representative picture of the intervention, than each method could alone.

DCM was good as the main research method. I used this method because it aims to represent the experience of *plwd* from their perspective, is an established method which is widely used within the care sector throughout the UK and internationally (University of Bradford, 2016b), and provides an abundance of data which enabled the researcher to capture changes in mood and emotion across time. This was demonstrated through results which showed some quite significant changes during one session (See Figure 5, Chapter 6, section 2) and differences across sessions when the *plwd* was observed twice (see Figures 8 and 11, Chapter 6, section 2).

The focus groups were good too. I used focus groups because I wanted to hear the voice of *plwd* without putting any pressure on individuals; previous researchers have found that there is less pressure on *plwd* to contribute in a focus group than in an interview (Hubbard et al., 2003). Focus groups have been found enjoyable for *plwd* (Casey & Murphy, 2014; Bamford & Bruce, 2002), which was the case in the current study; *plwd* appeared to enjoy them, enjoying jokes and laughter. Participants appeared relaxed, and interacted with each other . The pictorial prompts depicting the food were effective, as found by Bamford & Bruce, (2002); eliciting a number of comments from *plwd).*

There were however challenges faced using DCM as a research method, and focus groups, these will now be discussed alongside strategies implemented to overcome them, and lessons learned

9.3.2.1 Challenges of Using DCM as a research tool

Completing the training and achieving IRR with a second mapper was challenging. The training was delivered at Bradford University, approximately twice a year so I had to schedule the training as close to the intervention implementation as possible. I completed the training during May ahead of the intervention which was implemented in August. This schedule allowed time between the training and the implementation for me to become more familiar with the method, and to find another mapper who I could complete some mapping with, for practice and to achieve Inter Rater Reliability using DCM, with them. I approached the Head DCM trainer at Bradford who provided a number of suggestions; however, I then learned that the O/T that we had appointed to the project was a trained mapper which enabled us to map together and achieve the necessary IRR. Scheduling these events to coincide with the project dates was challenging, however this enabled me to gain the necessary skills and confidence to use the method effectively during the study. Scheduling time for training and practice of DCM is a factor that a researcher who has not used the method before would need to consider, the first time that they use it.

As a new mapper I was able to map only 1 *plwd* per week, which was a drawback that was not foreseen at the project design stage, but became evident during DCM training. What this meant was that the DCM data gathered during the interventions provided a view of the experience of each *plwd* during one or two of the sessions that they attended, rather than a full picture of their experience throughout the duration of the intervention. However, this is typical of similar studies, IG interventions delivered over a period of sessions have typically mapped a selection of the activity sessions. I did consider mapping two *plwd* per session but there was a great deal of activity during the activity sessions, therefore I decided to map one *plwd* each session to ensure that I captured the detail of everything that happened relating to the *plwd* that I was mapping. There are benefits of this in the accuracy of the data, Kitwood (1997) suggested that accuracy improves if mapping one individual, rather than up to five, which DCM can accommodate. I also had other data gathered from *plwd* who reported on their own experience, and care staff who reported on their observations during the intervention, which again illustrates the value of adopting a Mixed Methods framework. I became more experienced as the project progressed, therefore if I were to conduct similar research in the future, I would build resources into the research plan to complete some further practice, which would enable me to map up to five *plwd* simultaneously, as DCM protocol allows.

9.3.2.2 Reflections on the pre-test/post-test design

The pre-test post-test design was challenging. The plan was to observe the residents for thirty minutes before the activity session, the duration of the session, and for thirty minutes after to calculate an average ME score at the three time points to explore any changes observed. In practice however, this was difficult to achieve. There were a number of things to prepare prior to each activity session such as; ingredients, utensils, and seating for example. Despite the prior planning there were some final details that required attention which meant that the researcher did not have time to complete DCM as planned before the activities started. As the weeks progressed however the research team, and the care home staff became familiar with the process which in turn became more relaxed, and the researcher was able to complete mapping before the activity sessions. The care staff worked hard to ensure that the residents were ready to join in with the intervention at the scheduled time, which meant that the residents were regularly sitting at the table sharing a cup of tea and waiting, when the research team arrived. Interestingly, as the weeks passed, the participants started moving to the table when they saw the research team arrive, which suggests that they remembered the research team and were eager to start. We therefore started the activities for them as quickly as we could to avoid a loss of interest, which meant that observations prior to the activity sessions were shorter than planned.

It is also difficult to pinpoint where the activity sessions ‘end’. When we finished the activity sessions the participants usually remained at the table eating and chatting whilst care home staff provided them with refreshments. Care home staff stated that this is what they would normally do at this time of the afternoon; I continued to map but it is challenging to draw an arbitrary line indicating where the activity/intervention finished, and the ‘normal’ activities of the day resumed. This issue was highlighted by Keating et al. (2018, p10) who said ‘sessions did not end abruptly but transitioned back into the daily life of the care home, for example tea was served at the end of many sessions residents began to leave ‘after a reminiscence arts session. To address this challenge, I considered the introduction given by the activity facilitator, as the ‘start’ point of the activities, and the point that the students left as the ‘end’ of the session. This meant that I could complete a pre-test post-test analysis to illustrate change, but that any change was likely to be minimal. Kol et al (2019) successfully used this design to assess an hour-long dance intervention for *plwd,* however this was not delivered in a care home therefore may not have faced similar challenges. The strength of using a MM approach for the study was evident here, as I had asked care staff if they had observed any changes in the mood and behaviour of *plwd* that lasted over time, which provided some data to draw conclusions. If I were to run a similar study in the future, I would reconsider this pre-test post-test design, and aim to gather baseline DCM data on another afternoon when residents had no activities provided, if this were practical. I would not gather DCM data ‘post-test’, but as I did in this study, ask carers whether they observed any changes that lasted over time.

Notwithstanding the challenges of using DCM, I would use it again as it provided very detailed data linking what was happening with the mood and engagement of *plwd* minute by minute.

9.3.2.3 Challenges of using focus groups with plwd

Challenges outlined by previous researchers were experienced during the focus groups; Bamford & Bruce, (2002) suggest that some participants may dominate the process, parallel conversations may happen; participants may engage in storytelling and, there are challenges interpreting data.

One *plwd* had the dominant voice during the IG focus group, however this was not to the exclusion of others, conversely this participant encouraged others to speak, by completing their sentences with a question, for example: '*I liked it all being prepared didn't we*?'. These comments typically generated agreement from students, which is data that may not have been offered without this input, and illustrates consensus amongst participants; illustrating consensus or difference is a strengths of focus groups (Denscombe, 2014, Wilkinson, 2015).

Parallel conversations were a feature of the RO focus group; One *plwd* did not answer any of the questions asked by the researcher but spoke quietly to the facilitator and other participants throughout the focus group, and made regular comments such as: *'very quiet here isn't it?* to nobody in particular. This *plwd* also made noises during the focus group by knocking utensils against their cup. These behaviours may have distracted other participants, however taken together suggest a desire to be heard, and deserve to be recognised as such. To overcome any challenges experienced I repeated questions as appropriate. One *plwd* told some stories during the focus group which did not relate to my questions. Some *plwd* faced communication challenges. There were times during the focus groups when residents found it difficult to say what they wanted to; for example, one *plwd* experienced some challenges answering the questions, however answered some unaided, and others with the support of other focus group participants. After thanks had been given at the end of the RO focus group all the participants clapped which is a universally accepted sign of enjoyment, and appreciation. The clapping lasted for four seconds which felt like a long time. For the participants who experienced challenges with their communication this was one way that they could send a clear message and make themselves heard, and as Kitwood (1997b) suggests they should be applauded for their ingenuity producing interactions which compensate for their cognitive impairment.

I designed the focus groups to be short for reasons outlined by George et al. (2014), who planned interviews with residents to last 3-5 minutes immediately after their intervention to reduce burden, support shorter attention spans, and minimise any frustration and confusion. This placed a limitation on the number of questions that could be asked and answered during the focus group, however the data generated was sufficient to gain an understanding of participants likes and dislikes relating to the intervention.

Notwithstanding the challenges discussed here, rich data was gathered, *plwd* appeared relaxed, and found the experience enjoyable. Whilst some *plwd* experienced communication challenges which meant that some of the data could not be used in the analyses completed, the signs were that *plwd* wanted to be heard, which was an aim of mine. I would use focus groups in the future with *plwd* for other research questions, but for a similar study to this assessing an intervention, I would replace the focus group with a few short questions at the end of each activity session.

9.3.2.4 Limitations of the research design

There are limits to the research design worthy of elaboration. First, activity sheets were completed by *plwd* only after the activity sessions, therefore there was no baseline data for the participants. Asking participants to complete the activity sheets before and after each session was considered however the researcher felt that this might be onerous for *plwd*. This meant that comparisons could not be drawn between how *plwd* felt before and after the activities therefore it is difficult to claim that the activity session improved the mood of participants, but the data does reflect the mood of *plwd* directly after the activity sessions which provided a good indication of how the activity session influenced their mood, while keeping the ‘load’ on *plwd* to a minimum.

There was no control group of students who did not attend the intervention to compare with, therefore it is difficult to claim that the intervention was the vehicle that brought about the change in students’ comfort with, and attitude towards *plwd*, The students may have experienced any number of events that influenced their attitudes towards *plwd* during the 5/6 week gap between the start and end of the intervention; the two points when they completed the DAS, however the results found in this study are consistent with many other IG interventions with *plwd* (Garrie et al., 2016, George at al., 2013, Lokon et al., 2017) therefore there is a strong basis for assuming that the intervention played a significant part in the change reported.

The Intergenerational focus group was novel, as I found no evidence of another having been undertaken in the literature. However, the students made few comments, which were typically ‘yes’, in agreement with a comment made by one of the *plwd.* This meant that the data gathered from them provided little insight to their experience, however I did not set out to explore the student experience per se, but whether their experience during the intervention changed their attitudes towards, and comfort with *plwd*, which was answered fully by the data gathered via questionnaires.

9.3.2.5 Limitations of the sample of participants

The sample size was small however this was a proof-of-concept exercise, and the sample size was ‘determined for reasons of convenience’ (and practicality) as in similar studies (DiBona, 2017, p.12). Isaki and Harmon (2015) for example, completed an IG intervention which involved 6 *plwd.* As in the study completed by (Isaka and Harmon (2015, p97) the small sample size enabled the researcher to ‘critically analyse the research methods used’

There is an apparent lack of diversity in the sample of *plwd*. The design of the intervention was shaped by Allport’s contact theory which aims to address prejudice, segregation, and stereotyping in relation to care home residents living with dementia, who are at risk of social isolation from the outside community. The theory is relevant to my research because of the risks of isolation that *plwd* may experience in a care home context when broader community and societal attitudes and behaviours towards them are coloured by prejudice and stereotyping about the condition itself. The risk is then that *plwd* become a segregated group in their own right, first and foremost because of their cognitive abilities. The main stratifying factor which was the subject of my research was therefore cognitive ability, and this was given priority over the more widely recognised factors of social stratification and segregation, that is culture, class or gender orientation and how these might influence the participants’ interaction with the intervention.

Even if these factors had been the prime focus of segregation, stereotyping and prejudice amongst *plwd*, it would have been very difficult to study their impact, based on the socio-demographic and culture nature of Wales' population as a whole and that of the population in residential situations.

Firstly, there is little ethnic diversity amongst the older population (60+) in Wales with 97.8% of older people identifying as White British, which increases to 98.8% in the population over 75 (The OPCW, 2021). This is reflected in the care home population, so there was little expectation of finding an ethnically diverse population within the care home sector to host the intervention. Furthermore, ethnic minority engagement in seeking or using health care and services for *plwd* is known to be negatively influenced by factors such as lack of knowledge about the condition, stigma, culturally preferred coping strategies and communication barriers (Giebel et al, 2014) and is therefore likely to influence poor uptake of residential care placements.

Secondly, due to differences in life expectancy, there was an expectation that more females would be living in care homes; effectively, the ratio of male to female residents 60-69 is 47:53, this difference increasing with age and in the 85 + groups this changes to 60:68 (OPCW, 2019). Thirdly, it would have been difficult to consider class as a discriminating factor as the nature of the funding structure for care home admission in Wales is selective based on an assessment of individual capital. This means that the final "choice" of care home will depend in large part on the outcome of a financial assessment, in other words, on a system of means testing (Wales Parliament, 2022). In Wales, if an individual has assets of over £50,000, it is likely that they will be liable for the whole cost of care, and will therefore have opportunities to select from a wider set of care homes than those whose care costs are supported by local authorities. As local authorities have set budgets for care provision it is unlikely that there will be diversity in the class profile of care home residents; those with higher assets are likely to have more choice, and the opportunity to live in a private care home if they wish. To explore class differences the study would therefore have needed to include one or more private care homes, and one or more not for profit care homes. Both care homes in this study were operated by a not-for-profit care provider.

In sum, as can be seen in Table 10 on page 117 the majority of participants who engaged in the study were white British females, therefore this sample is arguably lacking in diversity, but is nevertheless generally representative of care home residents in Wales. This said, in terms of transferability, the intervention could be adapted for *plwd* to include for example, different cultural dishes.

The sample may hold some bias: the *plwd* were identified by the gatekeeper; those *plwd* who the gatekeeper believed would enjoy and engage with it. This is a limitation of using a gatekeeper however this is essential in care home research, and would be a limitation of similar studies research (Hellstrom et al, 2007). Students were volunteers all from the Psychology department therefore were interested in engaging with *plwd*. Some researchers such as Blais et al. (2017) suggest that Service Learning has the potential for bias, Lokon (2017, p20) suggested that;' findings are based on a sample that is predisposed to participate in, enjoy, and benefit from SL'. This study sat somewhere between volunteering and Service Learning (where students gain course credits for engaging in a voluntary placement) so may involve some bias, however I suggest that some bias must be inherent in this type of study.

In the end, the students who joined the project were all from the Psychology department at Swansea University which begs the question of the representativeness of this group in relation to the student population as a whole. However, this was not a planned decision but one which evolved due to challenges experienced during the recruitment process. As the care home had no pre-formed connections with local colleges, the decision was taken to recruit students through Swansea University. I advertised the intervention as a voluntary opportunity on the Studentzone online platform which is open to all University students, approximately 18,000 at the time. However, no students contacted me through this channel. With the support of my second supervisor from Psychology, all students in this discipline were contacted by email, approximately 1,000. In total I received 19 replies and finally ended with 4 who were recruited. Whilst the focus of the research was not to explore in depth, the possible reasons for this bias in profile of students who did finally apply for the role, I have subsequently reflected on this, notably in relation to the literature. There appear to be a number of reasons which may explain this recruitment bias.

Firstly, few of the published IG articles include a process evaluation, therefore I found little in the literature relating to challenges of student recruitment. However, Lambert-Shute et al (2004) noted that sociology students did not volunteer to join an IG intervention completed with *plwd* in a care home, despite being invited at the beginning of the semester. Gerontology students, who received the same invitation, did volunteer. My thoughts on this are that the students may have judged the project would be hard to fit in with their schedules. This was the case in IG studies completed by Chung (2009) and Lambert-Shute et al (2004); feedback from students who had been involved in these interventions indicated that they had found it challenging to accommodate alongside their studies, and other commitments. Some potential participants hesitated to join the three-month programme completed by Chung (2009) for this reason. Although the current intervention represented a shorter time commitment, this may have played a part in their decision making.

Secondly, students may have found other aspects of the intervention unappealing, such as the nature of the tasks around food or volunteering in a care home. Alternatively. it may be the very factor that IG interventions aim to address which acted as a barrier to students volunteering, that is anxieties relating to interacting with *plwd*. The literature does support this as in IG studies involving students and *plwd*, students said that they had been anxious and fearful about working with *plwd* (Yamashita et al, 2011), and were worried about their ability to establish relationships with *plwd*, or were fearful that they would do something wrong (Lokon et al, 2012, p.346). During my research, care staff noted that some students were nervous during the early stages of the intervention.

These anxieties may be related to dementia stigma which is well documented, although the research relating to stigmatizing attitudes towards dementia amongst young people is mixed in its findings. Cheng et al (2011) found that young, educated people held more positive attitudes towards dementia than older, less educated people in a Chinese community, but in a systematic review of dementia related research completed in 6 countries including China, The USA and Israel, Herrmann and colleagues (2018) found that stigmatizing attitudes towards dementia appear worse among some specific sub groups including those with limited knowledge of dementia, and in younger individuals. Kane et al (2020, p.1702) also found that young adults: ‘showed significant negative attitudes towards people with dementia’ in Ireland. There is no way of knowing whether stigma was a factor amongst students when considering joining the project, however it is possible.

It is also possible that the care home context may have been unappealing to some students. There have been a number of cases of poor practice in care homes reported in the media such as Brithdir nursing home in Wales (Morris, 2021), and the public perception of care homes may be negatively affected by such reports. A poll completed in 2019 (IPSOS Public Affairs, 2020), found that 26% of the respondents from the general public agreed with the statement that ‘care homes are happy places to live’, compared to 97% of care home resident. In research involving focus groups which explored attitudes towards care homes amongst Oxford university students, only one in six expressed a positive perception of care homes. Negative words associated with care homes included; ‘smell, disabled, isolated and cheap’ (Castleoak and University of Oxford, 2021, The Carer, 2021). This negative perception may affect people who are considering working or volunteering in such contexts. In a survey completed in 2014 (Savanta ComRes, 2014), only 28% of people in the UK responded that they would be interested in volunteering in a care home

In sum, although there is no way of knowing why the recruitment of students to this project was so challenging, and what students may have perceived as barriers to engaging with the intervention, I have offered some possible explanations, several of which are supported by broader literature, including: the time commitment required, the nature of the activities, and negative attitudes towards *plwd* and/or care homes. Although I did not set out to explore this issue as part of this research, it would be an interesting topic to explore in future research.

9.3.2.6 Recruitment and Retention

Non-attendance meant that no DCM data was gathered on one *plwd* as they chose to attend only two of the four sessions. As they were third on my list to map, they would have been mapped on the third session which they did not attend. They did not attend the focus group either, however some data was gathered on this *plwd* from carers during the focus group, again illustrating the value of the mixed methods approach.

Recruitment and retention of residents (without dementia) was low with five out of a possible twelve sessions attended which represents an attendance rate of 41.75%. Three of the absences were due to issues with initial recruitment. Two residents with no diagnosis of dementia were recruited two weeks before the intervention started however, they subsequently decided that they did not want to join in before the intervention started. They had both expressed an interest in the intervention and attended an informal meeting in the unit where the activities were going to take place however at week three of the ‘pre-intervention’ visits I was told that they no longer wanted to be involved. The care staff then recruited another three participants (who they thought would enjoy the intervention) but this was not until week two therefore three places remained unattended during the first session. The care home manager felt that the recruitment of residents may have benefitted if done later and that it was done a bit too early.

Three residents attended session two of the intervention and engaged with it however two of them did not attend any additional sessions. Care staff did seek out the residents involved to see if they wanted to join in each subsequent session but they did not. The third participant attended all three sessions which were available to them after they had been recruited into the study.

9.3.3 Reflection on the complexities of separating out the variables of IG intervention and the intervention

Separating out the variables of intergenerational activity and the food activity in relation to how these contributed to wellbeing is challenging. This holds for other dimensions of the intervention as well, for example, the duration of the intervention, the nature of the activity, and the specificities of the care setting.

Recognition of this complexity was however, reflected in the choice of a mixed methods research design (see Chapter 4) and in its application. I designed the study to include a control condition with the aim of isolating the effects of the Intergenerational element. The findings illustrated differences between the groups, for example the Intergenerational group spent more time interacting with others, although the differences were not significant according to quantitative data. However, the qualitative data gathered illustrated some seemingly small events which appeared to make a big difference to the *plwd*. Perhaps most notably in the cases of ppt 3 and Ppt 9 who often sat quietly watching: both participants appeared to experience enhanced wellbeing on a number of occasions when other participants or care staff made jokes: for example, Ppt 3 winked, and Ppt 9 laughed. These moments, due to their brevity, did not always show as enhanced wellbeing using DCM as wellbeing scores are calculated as an average over 5 minutes. Nevertheless, these moments appeared special.

Results from the DCM meant I could observe, minute by minute, what was happening in the environment with the wellbeing experienced by *the plwd*, both with and without an intergenerational element. This was supplemented by observational data gathered from care staff and self-report data gathered from the participant. When brought together, these data enabled a more refined understanding of the interactions between IG and food elements of the intervention.

For example, the highest wellbeing DCM score was experienced by Ppt 12 during the indoor gardening session and an intergenerational setting. They experienced an ME of +5 during four timeframes whilst engaging in the gardening activity with a student, and during two timeframes when they were talking and laughing with the other students once the activity had ended. This suggests that the participant's wellbeing was enhanced through the pleasure of socialising with the students, something which was confirmed during the focus group. The participant spoke of their joy at meeting new people and learning all about them. Such inquisitiveness suggests this particular participant had a broader interest in the lives of younger people and would therefore have found the intergenerational element of the intervention naturally engaging, and hence a source of wellbeing. For this participation it would however, have been erroneous to attribute these high wellbeing scores to intergenerational activity alone as they also spoke during the activity of previous involvement in gardening.

In this particular instance, whilst the combination of different types of data clearly confirmed the positive impact of the intergenerational intervention on this participant's wellbeing, it is not possible to clearly separate out the role of the two elements in this outcome, a life's experience of gardening and the focused and time-specific engagement in an activity shared with younger people.

Other researchers such as Lokon et al (2017) have attempted to separate out the impact of variables of an Intergenerational art programme; 'Opening Minds through art' (OMA) designed for *plwd* living in long term care. Lokon et al (2017) observed 67 residents as they engaged in a variety of activities, or no activities at all, and found that the wellbeing of *plwd* improved most during the OMA activity. The key features which were found to make a difference were that; the activities were designed specifically for *plwd*, and the ratio of volunteers (younger generation) to *plwd* was 1:1. These findings indicate that the students made a difference to the wellbeing of *plwd*, however there is nothing in the findings that indicate that it was the ‘intergenerational’ factor that was key. It might have been that the individual attention of a volunteer of similar age to the *plwd* would have resulted in a similar effect.

On reflection, the control design of this thesis was useful in that it found that the activities were generally enjoyed by both groups of participants, and provided some indication that the Intergenerational element provided greater social interaction than the control, which resulted in increased wellbeing for residents living with dementia. However, when drawing comparisons between the groups there are many other differences between the control and intergenerational interventions that may also have had an impact on findings, including the care home in which it was completed, the care staff, and the personal characteristics of the participants involved. In this small-scale study, it is impossible to distinguish one variable from another in their influence on wellbeing. The mixed methods design meant that the findings were able to highlight a number of variables that were experienced together in a given scenario and their effect on wellbeing, but was unable to separate them out. The study represented ‘one moment in time’ for a small group of participants.

9.4 IMPLICATIONS FOR POLICY AND PRACTICE

It is recognised that having visitors in care homes is currently challenging due to the current pandemic of Covid19. In recognition of this, the implications of the research outlined below are for the future, one in which the pandemic has passed and visitors can return in an environment which is safe for all.

From a practice perspective, the study confirms the value of enabling participant engagement in food preparation and sharing as a means of enhancing wellbeing. Preparing and sharing food was found to be engaging and meaningful for participants. This is important because care home residents may experience malnutrition (NICE, 2011), therefore activities around food that encourage participants to eat may be useful, which concurs with findings of Jones and Ismail (2019).

The study highlighted the importance of ensuring that activities are carefully planned and match the abilities of the participants that they are designed for. The feedback from care home staff was that *plwd* enjoyed the activities because they were; 'easy'. This perception was as a result of careful planning. The design of the practical elements of the intervention in which residents were to be involved was informed by expertise from an occupational therapist (Pool, 2012) in conjunction with the knowledge provided by care staff. This feedback enabled me to plan the intervention to accommodate all participants. For example, I prepared 'recipe cards' for use by *plwd* with a 'planned' profile according to the PAL (Pool, 2012), and suggested that *plwd* with a sensory profile should be encouraged to smell fruit. Designed in this way, the intervention activities enabled all *plwd* to engage in some way according to their abilities. The practice implication is therefore that the design of this type of intervention needs to be adapted to its recipients. This will have resource implications for a care sector which has limited resources, including staffing. However, if the goal of care settings is to enhance wellbeing and integration of its residents, then my study provides evidence that interventions for food preparing and sharing are worth the investment.

A third practice insight gained through the intervention was that it became evident during the study that some residents were more capable of engaging in tasks than had been thought by care home staff. Some staff were surprised to see how well some of the participants had been able to butter bread. This insight subsequently motivated care staff to seek out more of these participatory activities for residents.

A fourth practice, and policy-linked insight was that the intervention facilitated choice for residents when it came to food (Older People's Commissioner for Wales, 2014). Prior to the intervention, much of the food had been brought to the unit by the kitchen staff; however, as a result of the intervention, care staff thought that there were some changes that could be made to this process to facilitate residents' choices (for example, residents participating in simple aspects of breakfast preparation by choosing spread). Similarly, care staff realised choice could be introduced by allowing residents to choose favourite recipes and ingredients.

Finally, the intergenerational element of this study has highlighted two things relating to risks of social exclusion for *plwd* in care settings. First, the study reinforces what other studies have begun to show through interventions focused on intergenerational activities other than food preparation and sharing (Sauer et al, 2014, for example) that the wellbeing of *plwd* benefit from interactions with those living beyond the immediate confines of the care environment. The intervention has shown the strength of using food as a means of facilitating interaction between *plwd*, care staff and those living beyond the institutional setting, and as a consequence, has proved valuable as a mechanism with the potential to reduce social exclusion for those living in care settings.

Second, for the students involved, being active participants in the intervention has appeared to change their attitudes towards dementia, in a positive way. There is therefore the potential to see the intervention as a mechanism for reducing negative social perceptions and stigma surrounding cognitive impairment. Inherent to the students' involvement in this study has been an element of "training" and learning.

The results of this study are timely as Wales now has a cross party IG group consisting of politicians from across the Senedd, key academic researchers, practitioners with experience of running intergenerational projects, and representatives of older and younger people, including Wales' Older People's and Children's commissioners. This group was formed in November 2020 and aims to; promote intergenerational solidarity and IG projects, and understanding between generations, with this in mind the group explores evidence with the aim of developing good practice, and policy proposals which will benefit both older and younger generations (Welsh parliament, 2021) The findings from this thesis suggest that activities based on preparing and sharing food, and involving university students and care home residents living with dementia would be an area with potential on which to focus.

The findings of this thesis illustrate the benefits of involving care home residents in the preparation of their own food. Residents could be provided with the opportunity to engage in growing their own vegetables, and preparing meals as suggested by the Older People's Commissioner for Wales (2014), and by The Welsh Government (2017). This would enable an element of choice for residents, which fruit to include in their fruit salad for example.

The participants in this IG intervention appeared to enjoy the afternoon visits with students as an occasion which would suggest that afternoon tea with visitors of all ages; friends, family and volunteers would be engaging for residents. This is also suggested by The Welsh Government in their document entitled: ‘Creating a positive dining experience’ (Welsh Government, 2017).

The intervention appears to have improved attitudes towards *plwd* amongst students, therefore indicating that more such initiatives would be positive. The results from the Service-Learning studies reviewed in this thesis also suggest that there are benefits to be had in raising awareness of *plwd* amongst students which may have a positive influence on their career choice. Results of the literature review completed at Chapter 3 suggest that there are few university placements in care homes in Wales; none that have been evaluated. This is important as there are many vacancies in care at the moment including care homes. The government have recently appointed Care Home Education Facilitators to facilitate placements in care homes for Healthcare students, which would help ‘train’ and develop the Healthcare workforce of the future. This thesis indicates the potential value of this initiative.

In sum, from a policy and practice perspective, the evidence drawn from the findings of this study suggest that the design of any intervention needs to be bespoke, or adapted to, the specific individuals and environment in which it will be used, if it is to be of benefit to their wellbeing. The evidence also shows that by encouraging *plwd* to become involved in preparing their own food, there is potential to make *plwd* feel or regain a sense of usefulness and engagement, and to have opportunities to exercise agency through choice. Encouraging students to engage in Intergenerational initiatives and placements has the potential to increase awareness of dementia within this population and provide them with greater insight into careers in social care.

9.5 THE UNIQUE CONTRIBUTION THAT THE THESIS MAKES TO CURRENT KNOWLEDGE

This thesis has made several contributions to this body of knowledge and contributes to a much-needed evidence base. It was completed in Wales, whereas the majority of research in this area has been conducted in America with a few studies completed in China, Australia, and European countries including England. The findings indicate that benefits of IG interventions found in American studies, such as an improvement in the knowledge and attitudes of students towards dementia, and enjoyment and engagement for *plwd* (Lokon et al., 2012; Lokon et al., 2017; George et al., 2013; George et al., 2014; Sauer et al., 2014; Yamashita et al., 2011) can be realised in Wales.

This study offers additional nuanced insights that similar studies have not provided. For example, the observational nature of DCM meant that subtle changes in the mood and engagement of *plwd* could be recorded alongside reasons for these changes. For example, I found that a gentle smile indicated an increase of wellbeing in participant three whose facial expression was for the most part neutral. By careful observation I was able to pinpoint that the smile was related to the arrival, or an interaction with the students.

At the time of design there were limited studies involving IG based on preparing and sharing food in the literature. A few involved a narrow focus (an omelette or baking for example) (McNair & Moore, Jarrott & Bruno 2010). Harris & Caporella (2014, p.279) said of their IG choir that; ‘Music was the vehicle that brought these two groups together’, in this intervention it was food, which was found to form a good basis for the activities. The intervention provided *plwd* with the opportunity to make new relationships with students from outside of the confines of the care home, whilst preparing or sharing the snacks. The activities also provided *plwd* the opportunity to reminisce about their cooking and gardening experience which simultaneously enhanced their wellbeing; Participant 12 in particular enjoyed talking about their gardening experience. All participants engaged to some level during the intervention, whether they helped prepare the food, or simply remained at the table and watched. All participants ate something during the intervention; even those participants who chose not to join in with the food preparation, ate the snacks once prepared. In summary, the study illustrates the potential of food-based activities to enhance social connections, wellbeing, and physical health through nutrition, for care home residents living with dementia.

In addition, this thesis included the view of care home staff, which few IG studies have included. In essence, the care staff liked that the activities were quick and easy to deliver and the intervention prompted them to consider how the residents could become more involved in food preparation.

This thesis also made additional theoretical contributions to Kitwood's framework of needs which are discussed fully in section 9.2. In summary my findings illustrated the importance of attachment to people external to the environment in which they lived, amongst *plwd*.

In sum, an innovative IG intervention based on preparing and sharing food involving *plwd* and students based in a care home setting was completed in Wales. The food-based nature of the activities and the context of Wales are both relatively novel for IG interventions. The intricacies of the research design led to insights into designing IG interventions, enhancing wellbeing for *plwd* in a care home setting, and raising awareness of dementia amongst students in Wales.

9.5.1 *Comparisons to previous studies*

The aim of this study was not comparative either between the devolved nations or with international nations although comparative materials have been drawn on to consolidate the findings of this very small-scale study. The findings of this thesis have some distinct similarities and differences to the intergenerational interventions involving *plwd* and students which I reviewed in Chapter 3 section 1, which were mostly completed in America, and are discussed below.

Most previous studies of this nature focused on outcomes for students only, a minority focused on outcomes for students and *plwd*. My study was different in that it explored outcomes for students and *plwd,* plus the view of care home staff.

This thesis employed a similar methodology and reported similar findings to many of the IG interventions which assessed changes in the knowledge and attitudes of students towards dementia. The majority of these studies used a pre-test post-test design, incorporating a variety of data gathering tools, for example Chung (2009) used a self-esteem scale and a quiz, whilst Harris and Caporella (2014, 2018) used a word task, Garrie (2016), George (2013) and Lokon (2017) used DAS (O'Connor & McFadden, 2010). I prepared a questionnaire for students which incorporated the DAS (O'Connor & McFadden) and the word task used by Harris and Caporella (2014, 2018). My findings were similar to the IG interventions which used DAS (Garrie 2016, George, 2013, Lokon 2017), in that they all found an increase in the knowledge, attitude and comfort with dementia amongst students. Similarly, to Harris and Caporella (2014,

2018) I found a shift in focus from negative words prior to the intervention, to positive words post intervention.

Some studies supplemented the pre-test, post-test design with cross sectional data gathered from students after the intervention was complete, in the form of surveys (Wood et al, 2017) or focus groups (Lambert-Shute et al, 2004). I also used focus groups however, my study differed to others, in that it included an Intergenerational focus group attended by *plwd* and students. Lambert Shute et al (2014) used focus groups to explore the experiences of students whilst Harris and Caporella (2014, 2018) used focus groups to explore the experience of *plwd* and their family members, neither included an IG focus group. Some of the findings of this thesis corroborated the findings of Harris and Caporella (2014, 2018) which indicated that *plwd* and students had fun together. Harris and Caporella (2014, 2018) also found that *plwd* had experienced a lessening in social isolation: I found that *plwd* enjoyed meeting new people from outside of their care home. Whilst I did not measure social isolation per se these additional, external connections have the potential to address feelings of social isolation.

Of the IG studies which I reviewed, involving *plwd* and students, only two assessed the experience of *plwd.* Chung (2009) who completed their research in Hong Kong used a purely quantitative approach while Sauer et al (2014) who completed their research in America used a mixed methods approach. Chung et al (2009) utilised quantitative measures to assess changes in Qol, cognitive function and depression in *plwd*, and found an overall improvement in QoL and cognitive function, plus a reduction in depression amongst *plwd*. I adopted a different approach to this, using a mixed methods approach which assessed the impact of the intervention on the wellbeing of *plwd*.

I adopted a similar approach to Sauer et al (2014) who assessed the wellbeing of *plwd* during an IG art intervention (OMA), by using an observational data collection tool. However, whilst Sauer et al (2014) based their study on Lawton's model of wellbeing (Lawton,1983, 1994, 1997), I based mine on Kitwood's model of wellbeing. Sauer et al (2014) used a modified version of the Greater Cincinnati Chapter Well-Being Observation Tool (GCWBT) (Kinney & Rentz, 2005) whilst I used DCM (Brooker &

Surr, 2006). Sauer et al (2014) found that *plwd* in the OMA IG programme were more engaged and experienced more pleasure compared to *plwd* who completed the traditional arts intervention. My findings were similar; I found that *plwd* in the IG group spent more time in higher mood and less time disengaged than the RO group, however these differences were not statistically significant.

9.5.2 *The Welsh Setting*

The care homes in which this study was completed, focused exclusively on providing residential care and support for adults aged over 65. The care home settings in which the studies based in America and Hong Kong were completed were either; day care services (Harris and Caporella, 2014,2018, Lambert-Shute et al 2004, Lokon, 2017), day care services and the homes of community dwelling *plwd* (Chung et al, 2009), or care homes (George et al, 2013, 2014, Garrie et al 2016, Sauer et al, 2014, Wood et al, 2017). Some of these care homes (Garrie et al, 2016, Lokon et al 2012, 2017 and Yamashita et al 2011) were situated in continuing care communities which are communities that include independent living, assisted living, and nursing care. This is not a concept that has traditionally existed in Wales, although there are some care providers that are ‘at the forefront in their field’ which offer ‘retirement villages’ such as Campion gardens retirement village in the Gower, Swansea. This retirement village offers day care, assisted living, a convalescence and care hotel, a residential care home, and a children’s nursery on site. Most care homes in Wales are similar to the ones that housed the intervention for this study which only focus on residential, or nursing care for older adults.

The IG projects reviewed, which involved university students were all classified as Service Learning, which means that the IG activity, intervention or placement, was completed as part of a larger programme of study. To my knowledge, service learning is not a term that is used in Welsh universities, although a number of degrees include clinical placements in NHS settings such as a Masters in clinical psychology. In Wales practice placements are an integral part of a social work degree (Social Care Wales, 2022). Welsh universities may provide opportunities and encouragement for students to engage in voluntary placements, however these are not typically embedded in Health and Social care courses, nor on ageing and gerontology courses. At Swansea university, for example, The Swansea Employability Academy (SEA) promotes voluntary placements throughout the academic year and the Week of Work (WOW) programme, which usually runs in January/February offers students a one week, unpaid ‘taster’ placement within a wide range of organisations.

In sum, the context in which IG interventions have been completed elsewhere, in America in particular, differ from the Welsh context. American IG interventions have been reported in the academic literature from the late 1990s, which evidence many developments in the area of IP, including shared sites and Service-learning initiatives which are embedded into society. There is little in the literature which is based in Wales, where developments appear sporadic.

9.6 FUTURE RESEARCH

This research has produced innovative findings which contribute to both academic and practical knowledge and the results have highlighted several potential areas where further research can be carried out. This study was essentially a ‘proof of concept ‘therefore larger studies are recommended. The activities appealed to participants therefore the theme of preparing and sharing food could be developed to incorporate outdoor gardening, regional dishes, and favourite recipes suggested by participants. The findings from this study suggest that the perception of people living with dementia as ‘older’ remained amongst students after their involvement with the intervention. It would be interesting to complete IG interventions with a cohort of people living with young onset dementia to explore their potential for changing perceptions of dementia being related to older adults. It would also be interesting to explore the role of personalities, of the students and the activities facilitator as these were highlighted in the findings of this study. Future studies could adopt an approach similar to that adopted by Kirkland et al. (2014) who assessed the quality of interactions between the facilitator and participants.

CONCLUSION

This Phd study aimed to develop, pilot, and evaluate an intergenerational intervention based on preparing and sharing food, which linked university students with care home residents living with dementia. The aims of the intervention were to; enhance the wellbeing of care home residents living with dementia, who may be at risk of social exclusion, and raise awareness of dementia amongst the students. Although there is an increasing focus on IG interventions, including care home residents, in Wales there is currently little in the academic literature which explores such interventions. The majority of research into IG interventions within a care home context have been completed in America and have been based on creative activities such as art, singing, dance, and poetry for example. Little has been based on food-based activities, which have the potential to provide nutrition, meaningful activity, and a sense of living an ordinary life, for *plwd* in a care home context. Therefore, the intervention was innovative on two fronts, it was completed in a Welsh context, and was based on preparing and sharing food.

The study used a mixed methods approach to explore the intervention from three perspectives; *plwd*, university students and care home staff. *Plwd* were observed during the intervention using DCM (Clare & Surr, 2006), and were invited to complete feedback sheets after each session. Students were asked to complete a questionnaire pre and post intervention which included the DAS scale (O'Connor & McFadden, 2010), and a phenomenological word task (Harris & Caporella, 2014, 2018) to assess changes in attitudes towards dementia. *Plwd* and students were invited to an IG focus group post intervention to discuss their thoughts, feelings, and experiences during the intervention. Care home staff were invited to a focus group post intervention to discuss their observations, and views of the intervention.

This was a complex intervention to design and implement, but one that benefitted *plwd*, and brought about change amongst students in their attitudes towards people living with dementia. *Plwd* generally experienced wellbeing during the intervention, with higher levels of social engagement observed during the IG intervention, compared to the resident only intervention. An increase in the knowledge of, and comfort with dementia was recorded amongst students, and increased recognition of *plwd* as individuals, rather than a homogenous group. Care home staff felt that the activities were appropriate for the care home setting, in particular they felt that the activities were quick and simple. In reality, the 'simplicity' was achieved with good planning, which ensured that the activities were suitable for the abilities of the participants. Some members of staff were surprised by the abilities of a number of *plwd* to complete the activities, which prompted them to consider future opportunities to engage *plwd* in the preparation of their own food.

This thesis generally found support for Kitwood's theories of wellbeing which capture the essence of wellbeing, and which were innovative at the time, however are quite elementary. My findings, in line with previous research, illustrates a more complex and nuanced picture. The findings generally support Kitwood's framework of needs however (1997) highlighted potential elaborations of the theories in two areas. Firstly, Kitwood (1997) suggested that *plwd* have five needs (attachment, occupation, inclusion, identity, and comfort); the thesis found support for the addition of agency as a sixth need, which was suggested by Kaufman and Engel (2014). Support was also found for the theories of citizenship (Bartlett & O'Connor (2010) and embodied personhood (Kontos, 2004) which show potential to extend Kitwood's basic notions of personhood further, by introducing an understanding of *plwd* as those with agency. offering *plwd* the opportunity to become engaged in preparing their own meals is one way in which choice could be enhanced in the care home setting.

Secondly, Kitwood (1997) stated that attachment to people was a need for *plwd* which was necessary for wellbeing; this thesis built on this by highlighting the importance of attachments to people from outside the confines of the care home environment to enhance the wellbeing of *plwd*. In practice, this could mean providing more opportunities for *pwld* to engage with people from the outside world in a social setting: IG interventions provide this opportunity. This could take many forms, however one example, could involve inviting friends, family, and volunteers for afternoon tea.

Despite the challenges that are inherent in such a project it is important that interventions such as this are researched in the care home environment, which faces multiple barriers to inclusion and engagement for residents, including those living with dementia. The intervention demonstrated the power of inclusivity/ engagement for people living with dementia.

It is important that we do all that we can to maintain the wellbeing of *plwd* throughout their journey through life. The way in which we care for *plwd* says something about us as a society, around how we treat those in need. If nothing else, any one of us may develop dementia, therefore we are in a strong position now to be able to shape the type of care that we may hope for ourselves and our loved ones in the future.

This project involved the research team working collaborating with Health and social care providers, and volunteers to deliver a positive experience for residents living with dementia, and students. This illustrates what is needed to deliver such projects in the future, and the importance of working together to deliver wellbeing for *plwd*, we each have a role to play in this process. Researchers and universities need to create such research projects and health and social care staff need to support and encourage them.

Relationship was found to be at the essence of the findings of this study but the importance of relationship extended beyond the academic endeavour. Good relationships between everyone involved in the project (research supervisor, researcher, activities facilitator, occupational therapist, care home managers, care staff and kitchen staff) were essential. The commitment of everybody involved to maintaining the wellbeing of *plwd* cannot be understated, as Kitwood (1997, p116) stated 'interventions cannot be separated from the personal and moral qualities of those that deliver it'

The increase in comfort with, and positive attitudes towards *plwd* amongst students experienced as a result of becoming involved in such an intervention are important too. As the numbers of *plwd* increase and associated challenges around providing good care for *plwd* increase alongside it, it is important that people, in this case, students, who are likely to provide care for people living with dementia, personally or professionally, are not fearful. It is important that people universally, but carers especially, recognise people living with the condition as individuals with differing preferences, personal characteristics, skills, knowledge, and abilities, in essence different care needs.

Universities are in a strong position to provide these types of opportunities as research projects or placements integrated into courses. There are many Welsh IG initiatives in place now encouraged by, and including input from the Welsh Government pairing schools and care homes, this could extend to pairings of universities and care homes. Intergenerational interventions involving university students and care home residents living with dementia appear to be increasing with a particular focus on medical and social care courses which is good, however there is room for more. IG interventions in the shape of placements could be embedded into all university programmes, IG interventions with university students and care homes appear to be increasing outside of medical and social care students, which is good however this could be extended to any subject area. The opportunity to become involved in this project was advertised to all students at Swansea University however it was only Psychology students that contacted me to express an interest. A range of activities could be linked to any area of study that might engage a wider range of students, which holds the potential to increase the comfort with and knowledge of *plwd* in the general workforce, not simply those hope to work in Health and Social care. This may involve some creative thinking on the part of university lecturers but is definitely something worth considering.

I have learned a great deal during the time that I spent producing this thesis about; the research process, the care home environment, and myself as a researcher and a family carer for a loved one living with dementia. However, the most impactful lesson that I learned was similar to that of the students involved; not to underestimate an individual living with dementia. The *plwd* in this study showed a desire and ability to meet new people, socialise, engage in activities, and have fun. They also showed their ability to make their voices heard, even when facing communication challenges. This is a valuable lesson, and one at the heart of person-centred care.

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APPENDIX 1: REVIEW PROTOCOL FOR INTERGENERATIONAL INTERVENTIONS INVOLVING OLDER ADULTS LIVING WITH DEMENTIA

Background

Intergenerational interventions including *plwd* have been used since the early 1990s This literature review sought to find out what components/ activities have been used as a basis for interventions, the aims and results of the interventions, and identify what methodologies have been used to evaluate the interventions.

Objectives

To answer the following questions which will form the evidence base on which to design the intervention. What effects do intergenerational interventions have on older adults with dementia and younger people? What factors of the intervention make a difference? What methodologies have been used to investigate the issue? How effective are they? And what theories have been used to explain the results?

Criteria for inclusion and exclusion of studies

Sources were included in this review if they evaluated an intergenerational intervention involving people living with dementia and children or young people under 25. Studies were excluded if they were not designed specifically for residents living with dementia, or if they involved familial interventions.

Types of studies

All study designs, for example randomised control trials in which a treatment group are compared with a control group (Bryman, 2016)/cohort studies/qualitative studies/quantitative studies.

Types of populations

Older adults with dementia, and: preschool children, school children, and college and university students.

Types of interventions or exposure

Interventions which involve any activity; (such as art, reminiscence, music), service-learning generic interventions were included. Clinical service-learning interventions were excluded.

Types of outcome measure

No specification was placed on the outcome measures which were used to evaluate the impact of the intervention.

Setting/context

Studies which have been completed anywhere in the world, but reported in English. Studies which have been completed in residential care settings, and/or day care, and in the community.

Search strategy for identification of studies

The following search terms and Boolean logic were used for each of the searches: “Intergenerational interventions” OR “Intergenerational activities” OR “Intergenerational Practice” OR “Intergenerational volunteering” OR “Intergenerational approach” OR “Intergenerational program*” OR “Service learning” AND Alzheimer’s OR Dementia. The terms mild cognitive impairment and memory loss were included in initial searches but did not yield many results therefore the decision was taken to remove the terms from the later searches. “Service learning” was included as initial scoping searches indicated that intergenerational interventions were regularly used in service learning. The only additional limits that were added to the search were that the content was written in English, no limits were put on dates or document type.

Study selection

All studies which met the inclusion criteria of; being written in English, and published within the previous 20 years.

Assessment of methodological quality

Only peer reviewed articles were included in the review.

Data extraction

The following details were extracted from each study and placed into a table: Authors, type of Intervention, duration of intervention, demographic of participants, whether assessments were made of *plwd*, and if so, what measure was used, what data was gathered, what measures were used, and the results.

Data synthesis

A narrative synthesis was used; a narrative synthesis uses words as opposed to figures. A narrative analysis aims to 'tell the story behind the findings of the various works that have been reviewed' (Denscombe 2014, p140).

Search strategy

Initial searches using the snowballing procedure as outlined by Wohlin (2014) were completed from July 2017 until March 2018. A start set of papers were identified by using the terms 'intergenerational interventions for people with dementia' in Google scholar. Once relevant articles were found the reference lists were checked (backward snowballing) and citations searched (forward snowballing). All new sources were preliminary read to ensure that they met the inclusion criteria for the review which is outlined below. If the new source met the inclusion criteria and had not been duplicated from an earlier source it was put to one side, and was processed in the same way at a later date. One article was processed at a time.

This was complemented with a database search completed during March 2018. A subject librarian was consulted before starting this search as suggested by Booth, Sutton, & Papaioannou, 2016. Questions for the literature review were devised and multiple terms were identified for each concept. The following databases were searched on March 17th and March 18th 2018: Web of Science, ASSISA, JStor, Psychinfo, Medline and CINAHLThis search returned 187 publications: Web of Science (51), ASSISA (5), JStor (30), Psychinfo (39), CINAHL (35), and Medline (27). A preview read was completed of all material and material that did not match the search inclusion/exclusion was discarded. All duplicates were also discarded. Articles that included intergenerational interactions/interventions with family members or care staff were excluded. Generic Intergenerational service-learning interventions which included activities such as art or music were included however service-learning clinical interventions were excluded. This search resulted in the identification of 37 articles which included peer reviewed articles based on research interventions, chapters in books related to those interventions (2) (Camp et al., 2005; Basting, 2003), literature reviews (1) (Galbraith et al., 2015), and commentaries on intergenerational programmes (3) (Black, 2011; Carpenter, 2015; George & Wagler; 2014).

Once relevant studies were retrieved the reference lists were checked to identify further studies for inclusion in the review. Citation searches were also completed of relevant studies using databases or Google scholar. Each time a new article was identified the same approach was followed. This was completed until no additional material was found.

Once key articles, researchers, research communities and clusters were identified active researchers were contacted for details of any additional studies not yet published. Social media sites were regularly visited for evidence of relevant research studies and interventions being completed. The researcher also used her personal knowledge in the search; she had presented at a number of conferences during this time and networked with other researchers exploring the same area. Active researchers met were contacted for details of studied being undertaken.

APPENDIX 2: TOM KITWOOD'S LIST OF INTERACTIONS WHICH AFFECT THE WELLBEING OF PEOPLE LIVING WITH DEMENTIA

Malignant Social Psychology

1.Treachery: The use of deception to distract or manipulate behaviour.

2: Disempowerment Not allowing or enabling a person to use the abilities they still have.

3: Infantilisation: Treating the person like a child.

4: Intimidation: Causing the person to feel fearful as a result of threat or physical power.

5: Labelling Referring to people inappropriately, for example ‘elderly mentally infirm’.

6. Stigmatisation: Treating the person as if they were an outcast.

7. Outpacing: Providing information or choices too quickly thus potentially making information difficult to understand.

8. Invalidation: Not acknowledging the reality of the person.

9. Banishment: Excluding the person either physically or emotionally.

10. Objectification: Treating the person as an object, for example during washing or dressing.

11. Ignoring: Conversing with others in the presence of the person as if they are not present.

12. Imposition: Forcing the person to do something.

13. Withholding: Failure to provide attention or meet an obvious need.

14. Accusation: Blaming a person for their misunderstanding or inability.

15. Disruption: Suddenly disturbing a person and interrupting their activity or thoughts.

16. Mockery: Making fun or joking at the expense of the person.

17. Disparagement: Telling the person that they are worthless.

Positive interactions in person centred dementia care

Social Interactions

1. Recognition: Acknowledging the *plwd* as an individual.

2. Negotiation: Consulting the *plwd* about their ‘preferences, desires and needs’.

3. Collaboration: Sharing a task with the *plwd*

4. Play: An exercise with the sole purpose of pleasure

5. Timalation: A sensuous or sensory interaction

6. Celebration: Joyful moments

7. Relaxation: Interactions in which the *plwd* feels relaxed, watching television together for example

Therapeutic Interactions

8. Validation: Accepting the reality of the feelings and emotions of the *plwd* and responding at a ‘feeling level’ (empathy).

9. Holding: Providing a ‘safe psychological space’ where the *plwd* can experience their emotions, even very strong ones such as anger, confident that the other person will not be pushed away. Holding may be psychological and physical.

10. Facilitation: Enabling the *plwd* to complete actions that they are unable to complete alone.

According to Kitwood facilitation becomes more therapeutic as dementia progresses and the individual living with it is less able to complete tasks alone.

Interactions in which plwd takes the lead

11. Creation: An interaction in which the *plwd* offers something of themselves to the social setting unprompted, starting to sing for instance.

12. Giving: An interaction in which the *plwd*; ‘expresses concern, affection, or gratitude’ for another’. This may be expressed as an offer to help or with a gift.

APPENDIX 3: IG INTERVENTION PROTOCOL

‘Tea for two generations’

Protocol for Intergenerational intervention

Carole Butler

Prifysgol Abertawe
Swansea University

HMT
HEALTHCARE MANAGEMENT TRUST

To: The Care Home Manager and staff

Thank you for your interest in this research project.

This programme of activities is being run as part of a PhD study at Swansea University which is being funded by The Healthcare Management Trust. The activity programme aims to bring together older residents with dementia with younger people from the community, to share activities related to preparing and sharing food.

We would like to work with you to complete the activity programme, which we hope you will find useful as service providers. Our proposals for the programme are set out in the following pages; however, we would welcome any comments or suggestions that you have to ensure that the project is completed smoothly.

Tea for two generations’

What activities will be involved?

Session	Session topic	Activity
Week 1	Getting to know you	Introductions: making ice cream from a ‘wartime’ recipe.
Week 2	Indoor Gardening	Planting cress, and herbs.
Week 3	Fruit	Making fruit salad. Sharing fruit salad and ‘wartime’ ice-cream
Week 4	Sandwiches	Making and sharing egg & cress sandwiches

Why did we choose those activities?

Previous studies have found that indoor gardening and food preparation are engaging activities for people with dementia (Lee & Kim, 2008, Jarrott & Gigliotti, 2010).

The activities have been designed, taken or adapted from a number of publications which provide advice and guidance for providing activities in care homes. A list of these publications is included at the end of this document.

How long will the activities last?

The programme consists of 4 practical activities which are scheduled to last approximately 45 minutes to an hour. The activities will be delivered on Monday afternoon between 2.30 and 4.30 for four weeks. The programme for each session has been designed in line with guidance provided by the College of Occupational Therapists (coot, 2015).

Who will be running the activities?

One member of the research team will demonstrate the activities, and facilitate the session. Carole Butler, the PhD student will observe the activities and write about the mood and engagement of residents using Dementia Care mapping (Kitwood & Bredin, 1992).

Will staff be involved in the activities?

We would like your help to support the activities; to observe the activities and to ensure that they are running smoothly. We would like your help to offer support and encouragement to residents and young volunteers, and to help if residents or young volunteers are experiencing difficulties with the activities, or appear anxious or distressed.

Who will provide the materials for the activities?

The research team will provide the ingredients, materials, and any additional implements required for the activities.

How many people will be involved in the activities?

Ideally the activities should be done in pairs; we would like your help to pair each resident who is living with dementia with a young volunteer. Based on previous research which suggests that smaller groups are better for people with dementia (Di Bona and Kennedy, 2015) we would like to have no more than two pairs on each table.

Are the activities safe?

Yes. We will be using common household implements during the activities, and activities will be supported by members of the research team and care staff. The likelihood of, and potential impact of harm is low. With safety in mind we have outlined some details that we will need to know about each resident joining the activities (see Appendix A). The researcher would like to work with you during her visits to gather this information.

Are the activities suitable for all residents?

We would like your help identifying residents who would be interested in the activities. We plan to use the Pool Activity Level (PAL) checklist (Pool, 2011) to assess residents' abilities, to ensure that the activities are suitable for all residents who would like to join in. We would like your help completing the checklist which will involve answering 9 questions about the level of abilities of residents in a number of areas, including eating.

The following pages outline our proposals for each of the sessions. The information in these pages includes a proposed schedule for each session, and a list of items required for the session and suggestions as to who would provide them.

Session 1: 'Getting to know you'

'Warm up'
The facilitator from the research team and the researcher will introduce themselves and tell the residents and young volunteers about the plans for this session. They will check that all participants are happy to continue.
Main Event/ Activity (facilitated by a member of the research team and supported by care home staff)
• 'Getting to know you': questions and reminiscence pictures • Making 'war time' ice cream
Conclusion
The facilitator from the research team and the researcher will: • Recap on session • Thank everybody involved • Ask participants for feedback on the session • Remind everybody involved of details of the next session

Equipment/supplies needed for the session

For the ‘getting to know you’ activity	
What do we need?	**Who will provide it?**
‘Getting to know you’ laminated question cards	The research team

Ice cream making	
What do we need?	**Who will provide it?**
Aprons and gloves	If residents have these, we could use them, if not the research team will provide them.
Laminated recipe cards	The research team
Ingredients: • Evaporated milk • sugar	The research team
Utensils: • Bowls to mix the ice cream in • Whisks to mix the ice-cream • Dessert spoons to measure the sugar	If the care home has these items and are happy to use them for the activities, we could do so. If not, the research team will provide them.

To freeze the ice-cream	
What do we need?	**Who will provide it?**
Freezer space	The care home
Individual containers	If the care home has these items and are happy to use them for the activities, we could do so. If not, the research team will provide them.
Labels	The research team

For ice cream tasting	
What do we need?	**Who will provide it?**
Already prepared ice cream to taste	The research team
Bowls and spoons	If the care home has these items and are happy to use them for the activities, we could do so. If not, the research team will provide them.

Session 2: Indoor gardening

'Warm up'

The facilitator from the research team and the researcher will introduce themselves and tell the residents and young volunteers about the plans for this session. They will check that all participants are happy to continue.

Main Event/ Activity

(facilitated by a member of the research team and supported by care home staff)

- Reminiscence pictures
- Planting cress and other herbs

Conclusion

The facilitator from the research team and the researcher will:

- Recap on session
- Thank everybody involved
- Ask participants for feedback on the session
- Remind everybody involved of details of the next session
- Hand out invitations/reminders to take away

Equipment/supplies needed for the session

<table>
<tr><th colspan="2">For the seed planting activity</th></tr>
<tr><td>What do we need?</td><td>Who will provide it?</td></tr>
<tr><td>Aprons and gloves</td><td>If the care home has these items and are happy to use them for the activities, we could do so.
If not, the research team will provide them.</td></tr>
<tr><td colspan="2">For the seed planting activity</td></tr>
<tr><td>What do we need?</td><td>Who will provide it?</td></tr>
<tr><td>Soil</td><td>The research team</td></tr>
<tr><td>Selection of herb seeds</td><td>The research team</td></tr>
<tr><td>Planting pots</td><td>If the care home has these items and are happy to use them for the activities, we could do so.
If not, the research team will provide them.</td></tr>
<tr><td>Tools:
• Watering cans
• Small trowels</td><td>If the care home has these items and are happy to use them for the activities, we could do so.
If not, the research team will provide them.</td></tr>
<tr><td>Labels to identify the pots</td><td>The research team</td></tr>
</table>

Session 3: Fruit salad

‘Warm up’

The facilitator from the research team and the researcher will introduce themselves and tell the residents and young volunteers about the plans for this session.
They will check that all participants are happy to continue.

Main Event/ Activity
(facilitated by a member of the research team and supported by care home staff)

- Preparing fruit salad
- Sharing fruit salad with ‘war time’ ice-cream

Conclusion

The facilitator from the research team and the researcher will:

- Recap on the session
- Thank everybody involved
- Ask participants for feedback on the session
- Remind everybody involved of details of the next session
- Hand out invitations/reminders to take away

Equipment/supplies needed for the session

To prepare the fruit salad	
What do we need?	**Who will provide it?**
Aprons and gloves	If the care home has these items and are happy to use them for the activities, we could do so. If not, the research team will provide them.
To prepare the fruit salad	
What do we need?	**Who will provide it?**
Recipe card with pictures	The research team
Ingredients: • Tins of pineapples • Orange juice • Selection of fruit	The research team
Utensils: • Large bowls to make fruit salad • Knives to cut fruit up • Fruit peelers • Individual bowls to serve fruit salad • Serving spoons • Spoons to eat with • Chopping boards	If the care home has these items and are happy to use them for the activities, we could do so. If not, the research team will provide them.
Labels to identify the pots	The research team

Session 4: Egg and cress sandwiches

‘Warm up’

The facilitator from the research team and the researcher will introduce themselves and tell the residents and young volunteers about the plans for this session.
They will check that all participants are happy to continue.

Main Event/ Activity
(facilitated by a member of the research team and supported by care home staff)

- Preparing egg and cress sandwiches
- Sharing the sandwiches

Conclusion

The facilitator from the research team and the researcher will:

- Recap on the session and the intervention… this is the last session
- Thank everybody involved
- Ask participants for feedback on the session
- Ask all participants if they would like to join in a focus group to answer a few questions about their views of the activities

Equipment/supplies needed for the session

<table>
<tr><th colspan="2">To prepare the sandwiches</th></tr>
<tr><td>What do we need?</td><td>Who will provide it?</td></tr>
<tr><td>Aprons and gloves</td><td>If the care home has these items and are happy to use them for the activities, we could do so.
If not, the research team will provide them.</td></tr>
<tr><td colspan="2">To prepare the sandwiches</td></tr>
<tr><td>What do we need?</td><td>Who will provide it?</td></tr>
<tr><td>Recipe card with pictures</td><td>The research team</td></tr>
<tr><td>Ingredients:
• Sliced bread
• Spread
• Pre boiled eggs
• Cress</td><td>The research team
N.B: We will use the cress that we planted for the sandwiches</td></tr>
<tr><td>Utensils:
• Plates
• Forks
• Knives</td><td>If the care home has these items and are happy to use them for the activities, we could do so.
If not, the research team will provide them.</td></tr>
<tr><td>Serviettes</td><td>The research team</td></tr>
</table>

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Provisional Timetable for Intervention Activities

It is proposed that the researcher visits the care home each Monday afternoon during the following timetable. The following schedule outlines proposed activities during each week.

Proposed date	Date	Activity
September 2017	18Th	• The researcher will ask care home staff whether they know of any groups of young people in the local area. • With support from the care home staff the researcher will contact the group to discuss the details of the research and to gain written permission to seek consent of young people in the group.
	25th	• The researcher will arrange a meeting with the young people to tell them about the research • The researcher will deliver a meeting to groups of young people in which she will tell them about the research. • She will hand out information sheets, consent forms and reply paid envelopes.
October 2017	2nd	• The researcher will talk with the care home manager about residents who may be interested in, and able to complete the activities. • The researcher will put up a small poster/s in the public area of the care home to advertise a meeting about the research. • The researcher will sit in the public area and talk to staff, residents and family members about the meeting, based on introductions by care home staff.
	9th	• The researcher will lead a meeting for staff, residents, and family members to inform them about the research. • Information sheets and consent forms will be handed out at the meeting for people who are interested, to take away and consider. This will give residents the opportunity to talk to family, friends and/or care staff about the research before they decide whether they want to join in.
	16th	• The researcher will sit in the public area of the care home to talk about the research to staff, residents, and family members. She will collect any consent forms that residents or family members want to hand in. She will also offer support to residents who

		are interested in the research, to complete consent forms.
	23rd	• The researcher will sit in the public area of the care home to talk about the research to staff, residents, and family members. • She will collect any consent forms that residents or family members want to hand in. • She will also offer support residents who are interested in the research, to complete consent forms. • The researcher will complete PAL assessments (As described on page 3 of this document), and information sheets for residents who want to join in (see Appendix A), with input from care staff.
	30th	• The young volunteers will be asked to complete the questionnaire before the activity session **Session 1: Introductions/ice cream**
November 2017	6th	**Session 2: Planting herbs**
	13th	**Session 3: Fruit salad**
	20th	**Session 4: Egg and cress sandwiches** • This session will be followed by a short focus group for residents and young people who have joined in the activities • The young volunteers will be asked to complete the questionnaire for the second time after this session
	27th	A focus group will be held for care home staff who have supported the intervention

APPENDIX 4: BEHAVIOUR CATEGORY CODES (BCC'S) IDENTIFIED IN THE DCM8 USER'S MANUAL

Code	Memory Cue	General Description of category
A	**Articulation**	Interacting with others verbally or otherwise
B	**Borderline**	Being engaged but passively (watching)
C	**Cool**	Being disengaged, withdrawn
D	**Doing for self**	Self-care
E	**Expressive**	Expressive or creative activities
F	**Food**	Eating or drinking
G	**Going Back**	Reminiscence and life review
I	**Intellectual**	Prioritising the use of intellectual abilities
J	**Joints**	Exercise or physical sport
K	**Kum and Go**	Walking, standing or moving independently
L	**Leisure**	Leisure, fun and recreational activities
N	**Nod Land of**	Sleeping, dozing
O	**Objects**	Displaying attachment to or relating to inanimate objects
P	**Physical**	Receiving practical, physical or personal care
R	**Religion**	Engaging in a religious activity
S	**Sexual expression**	Sexual expression
T	**Timalation**	Direct engagement of the senses
U	**Unresponded to**	Attempting to communicate without receiving a response
V	**Vocational**	Work or work-like activity
W	**Withstanding**	Repetitive self-stimulation of a sustained nature (not of other or outside of self)
X	**Excretion**	Episodes relating to excretion
Y	**Yourself**	Interaction in the absence of any observable other
Z	**Zero option**	Fits none of existing categories

(University of Bradford 2016, p.17)

APPENDIX 5: MOOD AND ENGAGEMENT (ME) VALUES IDENTIFIED IN THE DCM8 USER'S MANUAL

Mood	ME value	Engagement
Very happy, cheerful. Very high positive mood	+5	Very absorbed, deeply engrossed/engaged
Content, happy, relaxed. considerable positive mood	+3	Concentrating but distractible. Considerable engagement
Neutral. Absence of overt signs of positive or negative mood.	+1	Alert and focused on surroundings. Brief or intermittent engagement
Small signs of negative mood	-1	Withdrawn and out of contact.
Considerable signs of negative mood	-3	
Very distressed. Very great signs of negative mood.	-5	

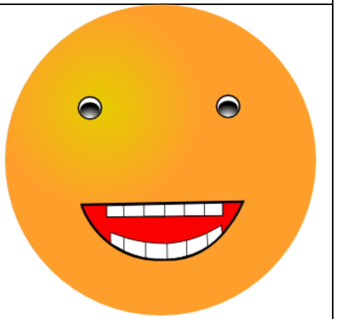
(University of Bradford, 2016a)

Appendix 6: Session feedback sheet

Thank you for joining in today’s session

Session Number: ________

Please tick the box below that shows most closely how you feel right now

Very sad	A bit sad	OK	Happy	Very happy
				

APPENDIX 7: STUDENT QUESTIONNAIRE

Enhancing person-centred care and wellbeing for older residents with dementia through intergenerational practice

Thank you for agreeing to complete this questionnaire. We are interested in finding out about the awareness of dementia, and attitude towards dementia amongst young people. This questionnaire should take about ten minutes to complete. Please read the instructions carefully and try to complete all the questions you can. Please be as honest and as accurate as you can throughout. There are no right or wrong answers.

Part A

1. Please enter your age __________
2. Please could you tick the most appropriate box for the following questions.
3. Please indicate your gender

Male		Non Binary	
Female		Other	

4. Do you know anyone with dementia?

Yes	
No	

5. If you answered yes to question 3 please indicate your relationship to that person

Grandparent	Other relative	Close family friend	Other

6. Approximately how often have you seen this person in the past year?

Not at all	A few times (less than once a month)	Monthly	Weekly	Daily

Part B ‘When you hear the word dementia, what images come to mind? Please write down 10 words that describe those images’

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____

Part C Using the scale below, please indicate the degree to which you agree with the following statements. Please read each item and then tick the appropriate response from 1 (strongly disagree) to 7 (strongly agree) that most closely reflects your response to each question. If you do not feel that a specific question is relevant to you please select the N/A option and move on to the next question.

		Strongly disagree	**Disagree**	**Somewhat disagree**	**Neither agree or disagree**	**Agree somewhat**	**Agree**	**Strongly agree**	**N/A**
1	It is rewarding to work with people who have dementia								
2	I am afraid of people with dementia								
3	People with dementia can be creative								
4	I feel confident around people with dementia								
5	I am comfortable touching people with dementia								
6	I feel uncomfortable being around people with dementia								
7	Every person with dementia has different needs								
8	I am not very familiar with dementia								
9	I would avoid an agitated person with dementia								
10	People with dementia like having familiar things nearby								

11	It is important to know the past history of people with dementia									
12	It is possible to enjoy interacting with people with dementia									
13	I feel relaxed around people with dementia									
14	People with dementia can enjoy life									
15	People with dementia can feel when others are kind to them									
16	I feel frustrated because I do not know how to help people with dementia									
17	I cannot imagine taking care of someone with dementia									
18	I admire the coping skills of people with dementia									
19	We can do a lot now to improve the lives of people with dementia									
20	Difficult behaviours may be a form of communication for people with dementia									

Thank you for your help

If you have any questions about filling in the questionnaire or about the study in general, you can contact the researcher Carole Butler on 342354@swansea.ac.uk.

APPENDIX 8: FOCUS GROUP TOPIC GUIDE FOR PARTICIPANTS

Thanks again for taking part in this group

I would like to find out what you thought about the activities

With your permission I will be recording the group

Ground Rules:

- Please could I ask you to respect each other's opinions
- And confidentiality; please do not share information outside of the group
- I cannot promise that other members of the group will not talk about it

Are you happy to go ahead?

Impressions of the Intervention

- Can you tell me about anything that you particularly liked about the activities?
- Can you tell me about anything that you did not like about the activities?
- Can you tell me about anything that you learned during the activities?

Impact of the Intervention

- Can you tell me how you felt ***during*** the activities?
  Prompt for explanations………why/tell me more/can you explain? Any examples?
- Can you tell me how you feel now the activities are finished?
  Prompt for explanations………why/tell me more/can you explain? Any examples?

Future involvement with the Intervention

- Is there anything that you think would make the activities better?
- Would you join in similar activities again?
  Why or why not?

Well, that is all of my questions thank you very much

Is there anything else that you would like to say?

There are sheets of paper in front of you to tell me about anything else that you would like to say privately. Please hand them back to me in the envelope provided whether you have written anything or not.

I would just like to thank you once again for your help with this research; it is very useful to us.

You have our contact details so if you have any further questions about the research or would like to request a copy of the group results, please contact us.

APPENDIX 9: TOPIC GUIDE FOR FOCUS GROUPS WITH CARERS/STAFF

Thanks again for taking part in our research we really value your views.

The purpose of this focus group is to explore your thoughts/ feelings/observations of the intervention/activities

I will be recording the focus group with your permission

Ground Rules:

- Please respect each other’s opinions
- Please respect the confidentiality of each other; do not share information outside of the group
- Although I ask this I cannot guarantee that other participants will not discuss your responses outside of the focus group

Are you happy to proceed?

Background information

- Could I start by asking you about any involvement that you have had with other activities provided here?
- How did this activity compare with others that you have been involved with?

Impressions of the Intervention (Broad topic 1)

- How many activity sessions did you attend?
- What was your general impression of the intervention/activities?
  Prompts: enjoyable? interesting? engaging for residents? length of intervention? Level of challenge?

Impact of the Intervention (Broad topic 2)

- Can you tell me what you think the residents thought of the intervention/activities? What did you see?
  Prompts: Fun/boring, interesting/dull, Too long/too short, Too easy/too hard, lot of interaction/little interaction

- Can you tell me about residents’ mood or behaviour ***during*** the intervention/activities? What did you see?
  Prompt for explanations………why/tell me more/can you explain? Any examples?
- Can you tell me about residents’ mood or behaviour ***since*** the intervention/activity? What have you seen?
- Can you tell me about anything that you liked about the activities/intervention?
- Can you tell me about anything that you did not like about the activities/intervention?

- Can you tell me about anything that you learned during the intervention?
  Prompts: Mood, Behaviour, Approach to caring, how you view residents

Sustainability of the Intervention (Broad topic 3)

- As a carer can you tell me about any challenges you faced being involved with the intervention/activity, or things that caused problems for you?
  Prompt for explanations………why/tell me more/can you explain?
- As a carer can you tell me about any benefits you felt as a result of being involved with the intervention/activity
  Prompt for explanations………why/tell me more/can you explain?
- Are there any changes that you think would make the intervention/activities better?
- How likely are you to repeat this activity or something similar?
  Why/why not?

Well, that is all of my questions thank you very much

Is there anything else that you would like to say?

Can I thank you once again for your help with this research; it is very useful to us.

You have our contact details so if you have any further questions about the research or would like to request a copy of the results, please contact us.

APPENDIX 10: ADDITIONAL INFORMATION SHEET FOR PARTICIPANTS

Swansea University
Prifysgol Abertawe

HMT

If there is anything else that you would like to tell us about the research study anonymously, please use the space below.

APPENDIX 11: EXTRACT FROM RESEARCH DIARY

APPENDIX 12: DEBRIEF FORM FOR STUDENTS

Debrief Form

Thank you for taking part in the research study.

In this study we were exploring the effects of an intergenerational intervention. The intervention aimed to bring young people from the community into a residential home to complete activities related to food, with residents with dementia. In essence, the study has two aims; we want to know whether the intervention improves the Quality of Life of people with dementia, and has any effect on the awareness of, and knowledge about dementia amongst the young people involved.

All data collected will be confidential, and participants will not be identifiable in any reports that are produced, published or presented at conferences. If you would like to withdraw from the study, please contact the researcher using the contact details below within a week of the final activity session.

If you experience any emotional upset during the research please speak to the researcher, a member of staff at the residential home, or your teacher.
There are services which offer confidential support for young people, the contact details of a number of these are listed at the end of this debrief sheet.

When results are analysed, you will be invited to a meeting at the residential home where the research took place. During the meeting the researcher will present group results to all involved in the result. As data was collected anonymously individual results will not be identifiable. If you are unable to attend the meeting but would like a copy of the group results, please contact the researcher.

If you have any questions or would like to withdraw from the study please contact:

Carole Butler: E-mail: [redacted]

If you have any concerns or complaints about this study, please contact the research Supervisor: Dr Sarah Hillcoat-Nalletamby
E-mail: [redacted]

Thank you very much for taking part in the study.

Providers of emotional support for young people

School, college, or university-based counsellor

(contact details to be sought and listed here by researcher once research links have been agreed with schools/colleges)

Kooth

Kooth provide online support for young people aged 11-19 (25 in some areas) at: https://kooth.com

Childline

Childline provide support for anyone under 19 by telephone on 08001111 or Online at: www.childline.org.uk

The Mix

The Mix provides emotional support for people aged 13-25 on telephone number: 08088084994

APPENDIX 13: INFORMATION SHEET FOR STAFF

Enhancing person-centred care and wellbeing for older residents with dementia through Intergenerational practice

You are being invited to take part in a research pilot study which aims to develop and pilot a programme of activities that involves two generations of people. The intervention will bring together older residents with dementia with younger people from the community to share activities related to preparing and sharing food (for example reminiscing about favourite recipes, foods, and traditions, and preparing and sharing a simple snack or meal together).

Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. Ask us if there is anything that is not clear or if you would like to know more.

What is the purpose of this study?
The research will explore any possible effects of the activity. In particular it will explore any changes in awareness and understanding of dementia by young people, and the quality of life of residents with dementia. This study forms part of a PhD for Carole Butler who is studying at the Centre for Innovative Ageing, Swansea University.

Why have I been invited to take part?
You have been asked to take part in this study because you fit one of our participant groups; residents, paid carers in the residential home, or young people living in the community.

Do I have to take part?
Your participation in this study is entirely voluntary. It is up to you to decide whether or not to take part.

What do I have to do?
You will be invited to an information event which will be held at the residential home, where I will explain the study in detail, and you will be able to ask any questions that you may have. If you still want to take part after the event, I will give you a consent form which I will ask you to return to the researcher who will return to the home a week later to collect them. The original signed and dated copy will be securely stored in the university and you will be given a copy to keep.

What will happen to me if I take part?

The Intervention

We are aiming to provide up to eight-hour long activity sessions (two sessions per week for four weeks). We will be providing two interventions; the first intervention will include residents only, the second will involve residents with dementia and young people from the community. With permission I will observe one or two residents with dementia before, during, and after the activities. I will anonymously record my observations using Dementia Care Mapping (DCM) which aims to 'gain a picture of the activities and well-being of people with dementia' (Brooker & Surr, 2006).

Focus group

You will be invited to attend a focus group at the end of the research project to tell us about your experiences during the activities. The focus group is expected to last about 30 minutes, and will include up to 6 carers who supported the activities with you. There will also be the opportunity for you to tell me anything else about the research anonymously; you will be provided with a sheet of paper to complete if you wish which you will be able to hand to the researcher in a sealed envelope.

After the research

When initial results have been analysed you will be invited to an information session at the residential home where the researcher will present group results. As data was collected anonymously individual results will not be identifiable.

What are the benefits of taking part in the research?

There may be no direct benefit to you however research shows that intergenerational activities have benefitted people involved. Such activities have been found enjoyable, and have resulted in benefits for young people and residents with dementia. Young people have gained new skills, and have reported increased awareness of, and improved attitudes towards dementia. People with dementia have reported higher mood levels and higher levels of positive engagement during intergenerational activities than non-intergenerational activities. Research has also shown that intergenerational discussions relating to food practices can have a positive impact on eating patternns. This study has the potential to improve young people's knowledge and awareness of dementia, and information from the study has the potential to enhance residential care for people with dementia.

What are the risks of taking part?

There are minimal risks in taking part in this study. Any risks are emotional, if you should feel upset during the research, please contact the researcher or your manager who will offer support and reassurance. This study has been reviewed approved by Swansea University Research Ethics Committee.

Will my taking part be kept confidential?

Yes, all information will be kept strictly confidential unless there are significant concerns about your safety or the safety of others. Data which is collected will be kept strictly confidential. Only the researchers will have access to the tapes and transcriptions of focus groups, which will be stored securely beyond the duration of the PhD (for approximately five years), after which the data will be destroyed. The computer used to store findings will be password protected. Participants' names will be anonymised in any published excerpts of the transcripts. All members of the focus group will be asked to keep what is talked about private, however this cannot be assured.

What happens if I change my mind?

Participation in this study is completely voluntary and you are free to withdraw at any time. If you withdraw, and your data is identifiable to the researcher, then you have the right to request that your data is not used.

What happens if something goes wrong?

If you are not happy about any part of the study then you can contact the Academic Supervisor Dr Sarah Hillcoat Nalletamby.

What will happen to the results of the research study?

The results of the study will form part of a higher degree thesis (PhD). The results may also be published in a relevant journal and may be presented at conferences. If reports or publications are generated from the study no names will be included.

Who is organising and funding the research?

This work is being organised by Swansea University Centre for Innovative Ageing. The work is being funded by The Healthcare Management Trust. The research will be carried out by Carole Butler (PhD student) and supervised by Dr Sarah Hillcoat-Nalletamby.

Complaints

If you have a complaint about this study please contact;
researchmisconduct@swansea.ac.uk

Who can I contact for further information?

This Information Sheet and the informed consent form contain important facts which you should consider when deciding whether you are willing to take part in this study. If at any time you have any questions about the study you should contact either the research investigator below or their supervisor.

Researcher: Carole Butler E-mail: [redacted]
Supervisor: Dr Sarah Hillcoat-Nalletamby
E-mail: [redacted]

APPENDIX 14 : INFORMATION SHEET FOR FAMILY MEMBERS

Swansea University
Prifysgol Abertawe

HMT

Enhancing person-centred care and wellbeing for older residents with dementia through Intergenerational practice

Your family member is being invited to take part in a research study which aims to develop and pilot a programme of activities that involves two generations of people. The intervention will bring together older residents with dementia with younger people from the community to share activities related to preparing and sharing food (for example talking about favourite recipes, foods, and traditions, and preparing and sharing a simple snack or meal together).

Before you decide whether you are happy for your family member to take part, it is important to understand why the research is being done and what it will involve. Please take time to read the information carefully. Ask us if there is anything that is not clear or if you would like to know more.

What is the purpose of this study?
The research will explore any possible effects of the activity. In particular it will explore any changes in; the quality of life of residents with dementia, and in awareness and understanding of dementia in young people. This study forms part of a PhD for Carole Butler who is studying at the Centre for Innovative Ageing, Swansea University.

Why has my family member been invited to take part?
They have been asked to take part as the manager at their residential home thought that they would fit the bill and enjoy the experience.

Do they have to take part?
Their participation this study is entirely voluntary. It is up to them to decide whether or not to take part.

What do I have to do?
Residents and family members are invited to a meeting at the residential home, where I will explain the study in detail, and you will be able to ask any questions that you may have. If your family member would like to take part, they will be given a consent form to sign and return to the researcher when she visits the home again the following week. The original signed and dated copy will be securely stored in the university and your family member will be given a copy to keep.

What will happen to my family member if they take part?

The Activities

We will be providing two interventions; the first intervention will include residents only, the second will involve residents with dementia and young people from the community. We are aiming to provide up to eight, hour long activity sessions (two sessions per week for four weeks). With permission we will observe one or two residents with dementia before, during, and after the activities. We will anonymously record our observations using Dementia Care Mapping (DCM) (Brooker & Surr, 2006) which aims to 'gain a picture of the activities and well-being of people with dementia'.

Focus group

Your family member will also be invited to attend a focus group once the activities are complete to tell us about their experiences during the activities. The focus group is expected to last about 30 minutes. There will also be the opportunity for people who completed the activities to tell us anything else about the research anonymously; they will be provided with a sheet of paper to complete if they wish which they will be able to hand to the researcher in a sealed envelope. Staff will be available to help with this if required. Alternatively, they will able to speak to the researcher confidentially.

After the research

When initial results have been analysed you and your family member will be invited to an information session at the residential home, where the researcher will present group results. As data was collected anonymously individual results will not be identifiable.

What are the benefits of taking part in the research?

There may be no direct benefit to your family member however research shows that intergenerational activities have benefitted people involved. Such activities have been found enjoyable, and have resulted in benefits for young people and residents with dementia. Young people have gained new skills, and have reported increased awareness of, and improved attitudes towards dementia. People with dementia have reported higher mood levels and higher levels of positive engagement during intergenerational activities than non-intergenerational activities. Research has also shown that intergenerational discussions relating to food practices can have a positive impact on eating patterns. This study has the potential to improve young people's knowledge and awareness of dementia, and information from the study has the potential to enhance residential care for people with dementia.

What are the risks of taking part?

There are minimal risks in taking part in this study. Any risks are emotional and care home staff will be present throughout the research to support residents. However, if a resident does become upset or anxious the staff will take the resident out of the activity and offer support and reassurance. This study has been reviewed and approved by Swansea University Research Ethics Committee.

Will my family member taking part be kept confidential?

Yes all information will be kept strictly confidential unless there are significant concerns about their safety or the safety of others. Data which is collected will be kept strictly confidential. Only the researchers will have access to the tapes and transcriptions of focus groups, which will be stored securely beyond the duration of the PhD (for approximately five years), after which the data will be destroyed. The computer used to store findings will be password protected. Participants' names will be anonymised in any published excerpts of the transcripts, and any data gathered from the observations. All members of the focus group will be asked to keep what is talked about private, however this cannot be assured.

What happens if my family member changes their mind?

Participation in this study is completely voluntary and your family member is free to withdraw at any time. If they withdraw, and their data is identifiable to the researcher, then they have the right to request that their data is not used.

What happens if something goes wrong?

If your family member, or you, are not happy about any part of the study then you can contact the Academic Supervisor Dr Sarah Hillcoat Nalletamby.

What will happen to the results of the research study?

The results of the study will form part of a higher degree thesis (PhD). The results may also be published in a relevant journal and may be presented at conferences. If reports or publications are generated from the study no names will be included.

Who is organising and funding the research?

This work is being organised by Swansea University Centre for Innovative Ageing. The work is being funded by The Health Management Trust. The research will be carried out by Carole Butler (PhD student) and supervised by Dr Sarah Hillcoat-Nalletamby.

Complaints

In the unlikely event that you feel that there has been less than optimal care of your family member please contact; researchmisconduct@swansea.ac.uk

Who can I contact for further information?

This Information Sheet and the informed consent form contain important facts which your family member should consider when deciding whether they are willing to take part in this study. If at any time they, or you, have any questions about the study you should contact either the research investigator below or their supervisor.

Researcher: Carole Butler E-mail: [redacted]
Supervisor: Dr Sarah Hillcoat-Nalletamby E-mail: [redacted]
[redacted]

APPENDIX 15: STUDY INFORMATION SHEET FOR RESIDENTS

Swansea University
Prifysgol Abertawe

HMT

Preparing and sharing food

I am asking if you would like to join in a research study. Before you decide, it is important that you understand what the study is about, why I am doing the study and what it will mean to take part. So please read this leaflet and keep it.

You can speak to other people about it if you want. Please ask me about it if you have any questions.

Why is the study being done?

This study forms part of a PhD for Carole Butler from Swansea University.

I would like to find out about activities which people in residential homes enjoy

Why have I been invited to join in?

You have been invited to join in because you live in this home.

Do I have to join in?

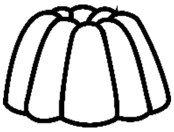
No. It is up to you. If you do not want to join in your care will not be affected.

What will happen if I join in?

If you want to take part I will ask you to sign a form saying that you are happy to take part

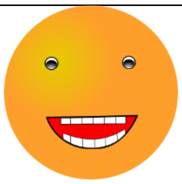
The activities

I will ask you to join in activities about food. This may mean talking about your favourite recipes or preparing a simple snack.   Other people from your home will join the activities with you. Young people may also join in some activities.



With your permission I will watch the activities. I will also watch what happens for a little while before and after the activities. I will write about what happens. Real names will not be used in any writing.

At the end of each activity you will be asked how you feel using faces like this.

Very sad	A bit sad	OK	Happy	Very happy
				

The focus group

I will also invite you to a short meeting. At the meeting I will ask you what you thought about the activities. Other people who joined in the activities will also be there.

After the study

I will invite you to another meeting where I will tell you what I found out

Will the study upset me?

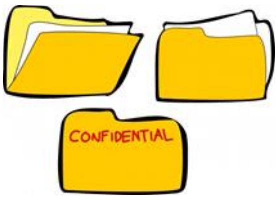
All activities are safe. The study has been checked by Swansea University Research Ethics Committee.

Will the study help me?

I cannot promise the study will help you but the information I collect may improve the care of people living in residential homes. People have found activities like these enjoyable; I hope that you will enjoy these.

Will you tell anyone what I said?

I will be writing about what you said but I will not use your name. People who read my writing will not know who said the words. I will keep anything that you say strictly confidential unless I am worried about your safety or the safety of others. I will ask other people in the group to keep anything that you say during the activities and discussions confidential too.



What happens if I change my mind?

Just tell me or the carers that you do not want to join in any more. You do not have to give a reason.

What happens if something goes wrong?

If you are unhappy about the study you can tell me or my Supervisor Dr Sarah Hillcoat Nalletamby. The staff at your home will help you do this.

What will happen to the results of the study?

The results may be published and may be presented at conferences.

If reports are published no names will be used.

Who can I contact for more information?

If you have any questions at any time, contact me or my supervisor. The staff in your home will be happy to do this for you.
Researcher: Carole Butler E-mail: [redacted]
Supervisor: Dr Sarah Hillcoat-Nalletamby
E-mail: [redacted]

APPENDIX 16: CONSENT FORMS FOR STAFF

Enhancing person-centred care and wellbeing for older residents with dementia through intergenerational practice

Researcher: Carole Butler PhD student, [redacted]

Please Initial Box

1.	I confirm that I have read, and understand, the information sheet dated January 2017 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2.	I understand that my participationis voluntary and that I am free to withdraw at any time, without giving a reason	☐
3.	I agree to take part in the above study; I agree to support the activities and take part in the focus group.	☐
4.	I agree to the focus group being tape-recorded, and agree that any words that I may use during the focus group can be used anonymously, in the presentation of the research.	☐
5.	The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me	☐
6.	I understand that anything I say during the focus group will be kept strictly confidential unless the researcher is worried about my safety or the safety of others	☐

I, ____ (PRINT NAME) consent to participate in the study conducted by Carole Butler, a PhD research student in the Centre for Innovative Ageing, Swansea University under the supervision of Dr. Sarah Hillcoat-Nalletamby and Professor Andrea Tales.

Signed: ________________________________ Date: ____________

Name of Researcher Date Signature

APPENDIX 17: CONSENT FORM FOR FAMILIES

Enhancing person-centred care and wellbeing for older residents with dementia through intergenerational practice

Researcher: Carole Butler PhD student, [redacted]

Please Initial Box

1.	I confirm that I have read, and understand, the information sheet dated January 2017 for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	☐
2.	I understand that my family member's participationis voluntary and that they are free to withdraw at any time, without giving a reason	☐
3.	I agree to my family member taking part in the activities and that the activities may be observed by the researcher	☐
4.	I agree that any notes made by the researcher during the observation can be used anonymously in the presentation of the research	☐
5.	I agree to my family member taking part in the focus group	☐
6.	I agree to the focus group being tape-recorded, and agree that any words that my family member may use during the focus group or on the paper provided afterwards can be used anonymously, in the presentation of the research.	☐
7.	The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me	☐
8.	I understand that anything that my family member says during the research will be kept strictly confidential unless the researcher is worried about the safety of your family member or others	☐

I, _________________________PRINT NAME) give consent for_______________ (PRINT NAME) to participate in the study conducted by Carole Butler, a PhD research student in the Centre for Innovative Ageing, Swansea University under the supervision of Dr. Sarah Hillcoat-Nalletamby and Professor Andrea Tales.

Signed: ______________________________ Date: ______________________

Please enter your relationship to the participant______________________________

Name of Researcher ___________________ Date______________________

Signature ____

APPENDIX 18 : CONSENT FORMS FOR RESIDENTS (ACTIVITIES)

Swansea University
Prifysgol Abertawe

HMT

Preparing and sharing food

Please Initial Box

1.	I understand about the activities	☐
2.	I have been able to ask questions	☐
3.	I understand that I do not have to join in the activities, and can leave at any time	☐
4.	I agree to join in the activities	☐
5.	I agree that the researcher can watch the activities and write about them	☐
6.	I understand that real names will not be used	☐
7.	The procedures about confidentiality have been explained to me	☐
8.	I understand that the researcher will keep anything that I say confidential unless they are worried about my safety or the safety of others	☐

I, ____NAME) consent to join in the study

Signed: ________________________ Date__________

Researcher: Carole Butler

E-mail: [redacted]

Signature: ____________________ Date: _______________

APPENDIX 19: CONSENT FORM FOR RESIDENTS: (FOCUS GROUPS)

Exploring activities for older residents with dementia

Researcher: Carole Butler PhD student,

[redacted]

Please Initial Box

1.	I have read, and understand, the information sheet dated January 2017. I have been able to ask questions.	☐
2.	I agree to take part in the focus group.	☐
3.	I agree to the focus group being tape-recorded	☐
4.	I agree that what I say in the focus group can be used in the research. My name will not be used.	☐
5.	I agree that any comments I make about the activities can be used in the research. My name will not be used.	☐
6.	The procedures about confidentiality have been explained to me	☐
7.	I understand that the researcher will keep anything that I say confidential unless they are worried about my safety or the safety of others	☐

I, ____ (PRINT NAME) consent to participate in the study conducted by Carole Butler, a PhD research student in the Centre for Innovative Ageing, Swansea University under the supervision of Dr. Sarah Hillcoat-Nalletamby and Professor Andrea Tales.

Signed: ________________________ Date: _____________

Name of Researcher	Date	Signature
___________________	_________	_____________________

APPENDIX 20: RECRUITMENT POSTER

Swansea University
Prifysgol Abertawe

HMT

Anyone for tea?

Would you enjoy activities to do with food?

We will do things like:

Talk about our favourite foods

Grow cress to use for our sandwiches

Carole will be here on

____

to tell you more about it
Family members are welcome to come along to this meeting

APPENDIX 21: STUDENT ADVERT ON UNIVERSITY WEBSITE AND E-MAIL

Dear …

I am a PhD student currently studying at Swansea University in the Centre for Innovative Ageing under the supervision of Dr Sarah Hillcoat-Nallétamby and Professor Andrea Tales.

I am currently undertaking research funded by The Healthcare Management Trust into Intergenerational interventions which join young people aged 16-24 with people with dementia living in residential care. I have designed an intervention which I aim to pilot in a local residential care home. The intervention will bring together older residents with dementia with younger people from the community, to share activities related to preparing and sharing food (for example talking about favourite recipes, foods, and traditions, and preparing and sharing a simple snack or meal together).

I am currently seeking reliable and dependable participants aged 16-24 who may be interested in taking part in this research which is scheduled to run on Monday afternoons from 23rd October to the 20th November 2017.

This intervention will provide volunteers with the opportunity to learn about dementia and to interact with people living with the condition. It will provide the opportunity to develop team working skills as volunteers will be working with residents, carers, and the research team. This is a good opportunity for those wishing to work in social care to interact with people with dementia in a care home setting. Students have found the experience of being involved in similar intergenerational interventions rewarding and fun.

I have attached an information sheet which has more information about the project. This information sheet is designed for people who may be interested in taking part; it tells you all about the project, and what it will mean for you if you decide to take part.

If you are interested in volunteering for the project, please contact me at the following e-mail address: [redacted]

Thanks

Regards

Carole

APPENDIX 22: CONSENT FORM FOR CARE HOME MANAGERS

'*Tea for two generations'*
An Intergenerational psychosocial intervention for people with dementia living in care

Thank you for agreeing to facilitate my PhD research project which has been funded by the Health Management Trust and is being run at Swansea University by Associate Professor Sarah Hillcoat-Nallétamby ([redacted]

[redacted]

For ethics purposes, I would be grateful if you could complete and sign the form below and return it to me (scanned by email or postal).

We look forward to collaborating with you on this exciting and innovative project

Care Home Manager consent form

I understand that …………… participation in this project will involve:

Please Initial box:

1.	Discussing and agreeing details of the intervention with the research team from Swansea University	☐
2.	Assisting us to identify suitable residents and staff to take part in the project and distributing the study information sheets to them	☐
3.	Providing consent forms which we will send to you, to all relevant parties and ensuring they are signed and returned to us before our research begins	☐
4.	Displaying project information in public areas of …….. and allowing the researcher access to public spaces to discuss the research with residents, family members and staff	☐
5.	Allowing the researcher, the use of a suitable location in which to conduct the intervention and focus groups, and ensuring that staff are present to support residents during the intervention and to participate in follow up focus groups.	☐

I understand that:

Please Initial box:

6.	The care home's participation in this research is entirely voluntary	☐
7.	The residents that take part in the study will be free to withdraw from the research at any time and without giving a reason.	☐
8.	As manager, I must keep the identity of all residents who participate confidential.	☐
9.	The identity of residents will be treated confidentially by the researcher and that all information will be stored anonymously and securely. All information appearing in the final report will be anonymous.	☐
10.	All residents who take part will have the option of withdrawing their data from the study, up until their data has been anonymised.	☐
11.	I am free to discuss any questions or comments I might have with either the researcher Carole Butler or the research supervisor Dr Sarah Hillcoat-Nalletamby.	☐
12.	I am free to contact the Swansea University Ethics Committee to discuss any complaints I might have.	☐

I, ………………………………………………………………… (NAME) consent to Carole Butler proceeding with this study with the supervision of Dr Sarah Hillcoat-Nalletamby.

Care Home ---

Signature of Care Home Manager…………………………………………

Date…………………………………………………….

PhD researcher: Carole Butler

Email: [redacted]

Research supervisor: Dr Sarah Hillcoat-Nalletamby

Email: [redacted]

Phone: [redacted]

APPENDIX 23: INFORMATION SHEETS FOR STUDENTS

Enhancing person-centred care and wellbeing for older residents with dementia through Intergenerational practice

You are being invited to take part in a research study which aims to develop and pilot a programme of activities that involves two generations of people. The intervention will bring together older residents with dementia with younger people from the community to share activities related to preparing and sharing food (for example talking about favourite recipes, foods, and traditions, and preparing and sharing a simple snack or meal together).

Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. Please take time to read the information carefully. Ask us if there is anything that is not clear or if you would like to know more.

What is the purpose of this study?
The intervention will explore any possible effects of the activity. In particular it will explore any changes in awareness and understanding of dementia by young people, and the quality of life of residents with dementia. This study forms part of a PhD for Carole Butler who is studying at the Centre for Innovative Ageing, Swansea University.

Why have I been invited to take part?
You have been asked to take part in this study because you fit one of the participant groups; residents, paid carers in the residential home, or young people.

Do I have to take part?
Your participationin this study is entirely voluntary. It is up to you to decide whether or not to take part.

What do I have to do?
If after reading this you still want to take part please e-mail the researcher Carole Butler at [redacted] ***with your name and address***. I will then send you a consent form which I will ask you to return to me in the envelope provided. The

original signed and dated copy will be securely stored in the university and you will be given a copy to keep.

What will happen to me if I take part?

The questionnaire

At the start of the research, you will be asked to complete a short questionnaire asking about your knowledge of, and attitude towards dementia. This should take you no more than 10 minutes. You will be asked to complete the same questionnaire at the end of the research project.

The Intervention

We are aiming to provide four-hour long activity sessions (one session per week for four weeks). You will also be asked to indicate how you feel at the end of each session on a simple tick sheet.

Focus group

You will also be invited to attend a focus group at the end of the research project to tell us about your experiences during the activities. The focus group is expected to last about 30 minutes, and will include people who joined in the activities with you. With your permission the focus group will be tape recorded. There will also be the opportunity for you to tell me anything else about the research anonymously; you will be provided with a sheet of paper to complete if you wish which you will be able to hand to the researcher in a sealed envelope. Additionally, you will be offered the opportunity to speak to the researcher confidentially.

After the research

When initial results have been analysed you will be invited to an information session at the residential home where the researcher will present the group results. As data was collected anonymously individual results will not be identifiable.

What are the benefits of taking part in the research?

There may be no direct benefit to you however research shows that intergenerational activities have benefitted people involved. Such activities have been found enjoyable, and have resulted in benefits for young people and residents with dementia. Young people have gained new skills, and have reported increased awareness of, and improved attitudes towards dementia. People with dementia have reported higher mood levels and higher levels of positive engagement during intergenerational activities than non-intergenerational activities. Research has also shown that intergenerational discussions relating to food practices can have a positive impact on eating patterns. This study has the potential to improve young people’s knowledge and awareness of dementia, and information from the study has the potential to enhance residential care for people with dementia.

What are the risks of taking part?
There are minimal risks in taking part in this study. Risks are emotional and care home staff will be present throughout the research, if you become upset or anxious please tell them or the researcher who will take you away from the group and offer you support and reassurance. They will also provide you with details of support services that offer emotional support to young people. This study has been reviewed approved by Swansea University Research Ethics Committee.

Will my taking part be kept confidential?
Yes, all information will be kept strictly confidential unless there are significant concerns about your safety or the safety of others. Only the researchers will have access to the tapes and transcriptions of focus groups, which will be stored securely beyond the duration of the PhD (for approximately five years), after which the data will be destroyed. The computer used to store findings will be password protected. Participants' names will be anonymised in any published excerpts of the transcripts. All members of the focus group will be asked to keep what we talk about private, but this cannot be assured.

What happens if I change my mind?
Participationin this study is completely voluntary and you are free to withdraw at any time. If you withdraw, and your data is identifiable to the researcher, then you have the right to
request that your data is not used.

What happens if something goes wrong?
If you are not happy about any part of the study then you can contact the Academic Supervisor Dr Sarah Hillcoat Nalletamby.

What will happen to the results of the research study?
The results of the study will form part of a higher degree thesis (PhD). The results may also be published in a relevant journal and may be presented at conferences. If reports or publications are generated from the study you will not be identified.

Who is organising and funding the research?
This work is being organised by Swansea University Centre for Innovative Ageing. The work is being funded by The Healthcare Management Trust. The research will be carried out by Carole Butler (PhD student) and supervised by Dr Sarah Hillcoat-Nalletamby.

Complaints
If you have a complaint about the research please contact;
researchmisconduct@swansea.ac.uk

Who can I contact for further information?
This Information Sheet and the informed consent form contain important facts which you should consider when deciding whether you are willing to take part in

this study. If at any time you have any questions about the study you should contact either the research investigator below or their supervisor.

Researcher: Carole Butler E-mail: [redacted]
Supervisor: Dr Sarah Hillcoat-Nalletamby E-mail: [redacted]
[redacted]

APPENDIX 24: CONSENT FORMS FOR STUDENTS

Enhancing person-centred care and wellbeing for older residents with dementia through intergenerational practice

Researcher: Carole Butler PhD student, [redacted]

Please Initial Box

1.	I confirm that I have read, and understand, the information sheet dated November 2016 for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	☐
2.	I understand that my participationis voluntary and that I am free to withdraw at any time, without giving a reason	☐
3.	I agree to complete the questionnaire, and that any words that I use on the questionnaire can be used anonymously, in the presentation of the research.	☐
4.	I agree to take part in the activities	☐
5.	I agree to take part in the focus group	☐
6.	I agree to the focus group being tape-recorded, and agree that any words that I may use during the focus group or on the paper provided afterwards can be used anonymously, in the presentation of the research.	☐
7.	The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me	☐
8.	I understand that anything I say during the focus group will be kept strictly confidential unless the researcher is worried about my safety or the safety of others	☐

I, ____ (PRINT NAME) consent to participate in the study conducted by Carole Butler, a PhD research student in the

Centre for Innovative Ageing, Swansea University under the supervision of Dr. Sarah Hillcoat-Nalletamby and Professor Andrea Tales.

Signed: _________________________________ Date: __________________

Name of Researcher _______________ Date: __________________

Signature _______________

APPENDIX 25: DEBRIEF FORM FOR STAFF

Debrief Form

Thank you for taking part in the research study.

In this study we were exploring the effects of an intergenerational intervention. The intervention aimed to bring young people from the community into a residential home to complete activities related to food, with residents with dementia. In essence, the study has two aims; we want to know whether the intervention improves the Quality of Life of people with dementia, and has any effect on the awareness of, and knowledge about dementia amongst the young people involved.

All data collected will be confidential, and participants will not be identifiable in any reports that are produced, published or presented at conferences. If you would like to withdraw from the study, please contact the researcher using the contact details below within a week of the final activity session.

When results are analysed, you will be invited to a meeting at the residential home where the research took place. During the meeting the researcher will present group results to all involved in the result. As data was collected anonymously individual results will not be identifiable. If you are unable to attend the meeting but would like a copy of the group results, please contact the researcher.

If you have any questions or would like to withdraw from the study please contact:

Carole Butler: E-mail: [redacted]

If you have any concerns or complaints about this study, please contact the research Supervisor: Dr Sarah Hillcoat-Nalletamby
E-mail: [redacted]

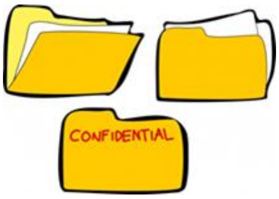
Thank you very much for taking part in the study.

APPENDIX 26: DEBRIEF FORM FOR RESIDENTS

Debrief Form

Thank you for taking part in the research. I wanted to find out whether you would enjoy the activities.

I will keep anything that you told me strictly confidential.



If reports are published no names will be used.

If you do not want your information to be used, please tell me within a week. The care staff will help you do this.

When I have finished writing I will invite you to a meeting at your home to tell you what I found out.

If you cannot come to the meeting but would like to know what I found out please ask me. If you have any other questions, please ask me.

The staff in your home will be happy to do this for you.

My e-mail address is: [redacted]

If you have any concerns or complaints about this study, please contact: Dr Sarah Hillcoat-Nalletamby

E-mail: [redacted]

The staff in your home will be happy to do this for you.

Thank you very much for taking part in the study.

APPENDIX 27: KEY RESEARCH ACTIVITY

2016

September	Initial e-mail contact made between project supervisor and Head of Residential Care (HORC). Initial interest in collaboration expressed by HORC.
November	Initial meeting with HORC, project supervisor and researcher to discuss broad plans for intervention and assess potential interest of care home group. Interest agreed at the meeting. The researcher was invited to visit three care homes run by this operator.
December	One care home visited: Provisionally agreed as a research site for the RO intervention.
2017	
February	Two further care homes visited. Provisional agreements made to use one of the homes as a research site for the IG intervention
May	Dementia Care Mapping Training completed
June	Second meetings with care homes: To meet supervisor and agree details and dates of the intervention Activities facilitator appointed to project (MSc Psychology student) OT appointed to project. First meeting with Swansea University Employment Zone to discuss student recruitment
July	Recruitment and preparation process completed at care home for RO intervention
August	Protocol for activities finalised Resident only intervention completed at care home
September	Focus groups completed for RO intervention
October	IG activities/intervention: Recruitment and preparation process at care home ……Student recruitment completed
November	IG/Intervention completed at care home
December	Focus groups completed for IG intervention

APPENDIX 28: THE DCM RULES FOLLOWED TO ALLOCATE APPROPRIATE BCC AND ME IN THIS THESIS

Three rules were followed, in order to identify the most appropriate ME value. If both the mood and engagement values were positive, I followed two rules. Rule 1 states: *Where the values for mood and engagement are the same, record that ME value.* An example is shown in map 2 timeframe 12, when the *plwd* was very engrossed in planting the seeds (Engagement = +5) whilst laughing out loud (Mood = +5). As both values were the same +5 was allocated; (V+5). If rule 1 did not apply I moved to rule two which states: *If the mood and engagement values are different then choose the highest value*. An example can be seen in map 1 timeframe 7, when the *plwd* was concentrating on eating the ice-cream (+3) with a neutral facial expression (+1). As +3 is the highest value, this was allocated; (F+3). If the *plwd* exhibited positive engagement but negative mood, I followed rule 3 which states: *If engagement is positive but mood is negative, the negative mood takes priority and is coded*. An example is shown map 2, timeframe 8, when the *plwd* looked a little uncomfortable (-1) as they focused, briefly, on putting the gloves on (+1). The negative mood value was therefore allocated to the BCC; (D-1).

Once a BCC was allocated an ME value they remained together, as one piece of data, for example (F+1). It was common for *plwd* to engage in a number of different behaviours during a 5-minute timeframe; in these cases, the four 'operational rules' included in the DCM protocol were followed to decide which BCC and accompanying ME value was the most appropriate to record.

Rule one states that BCC's with higher potential for positive ME are prioritised. In the following example taken from timeframe 8 of map 2, the participant engaged in (U-1) for approximately two minutes and (V+1) for three minutes. As V has high potential it took priority, and the code V+1 was allocated.

U	U	V	V	V
-1	-1	1	1	1

If both BCC's were of the same potential rule 2 was followed, which states that the BCC which the participant engaged in for *the most time* must be recorded. In the following example taken from timeframe 9 in map 8 P and F are both high potential categories but the participant engaged in P-1 longer, therefore this was coded.

F	F	P	P	P
1	1	-1	-1	-1

If both codes were of the same potential and were engaged in for similar amounts of time rule 3 was followed, which states that the *most extreme value* (whether positive or negative) must be recorded. In the following example taken from Map 7 timeframe 15 the participant spent two minutes in A and two minutes in F which are both high potential categories. The highest ME recorded was associated with the A therefore A+5 was recorded.

A	A	F	F	K
1	5	3	3	3

If two codes were of the same potential, were engaged in for similar amounts of time, and had the same extremity value rule 4 was followed. Rule 4 states that the behaviour engaged in for the *latter part of the timeframe* should be recorded. In the following example taken from timeframe 9 of map 4 the participant engaged in D and V with high potential for similar amounts of time. The same ME values were experienced during both BCC, therefore rule 4 was applied and V+1 was recorded as this was the last code recorded during the timeframe.

B	D	D	V	V
1	1	1	1	1

To conclude, the DCM protocol produced by Bradford University (2016) was followed to allocate an appropriate BCC and ME for each 5-minute timeframe represented in the maps.

APPENDIX 29: DCM NOTES

DCM notes for resident only intervention week 1

14:56-15:00: The researcher completes introductions, gains assent from *plwd*, and the intervention begins. Participant 1 says;'I don't like cooking', and 'I like ice-cream'. The activities facilitator hands out reminiscence materials. The participant looks at the materials and talks to a member of care home staff

15:01-15:05: The activities facilitator asks some questions including; 'what is your favourite food? and; 'What is your favourite drink?'. Participant 1 responds; 'I like anything' and smiles. The participant takes the reminiscence book from the member of care home staff, puts their glasses on and flicks through the book, whilst smiling and talking.

15:06-15:10: Participant 1 yawns and sits quietly engaged but passively watching

15:11-15:15: The Participant is supported by a member of care home staff to put their apron on and wash their hands. One of the care home staff starts to sing and the participant joins in. They leave the room with a member of care home staff.

15:16-15:20: The participant is absent

15:21-15:25: With the support of a member of care home staff Participant 1 returns, puts their apron back on, and washes their hands. They pour milk into a bowl, add sugar, and mixes it, concentrating throughout. They pass the bowl to another participant to mix and watch the participant as they whisk the mixture.

15:26-15:30: Participant 1 states that they want to go now, but then adds some sugar, leans forward and stirs the mixture. The ice-cream mixture does not thicken and is put to one side. A variety of flavoured ice creams are brought to the table. The participant looks excited and smiles

15:31-15:35: The participant tastes the strawberry ice cream; their face is neutral but they are engaged with the activity.

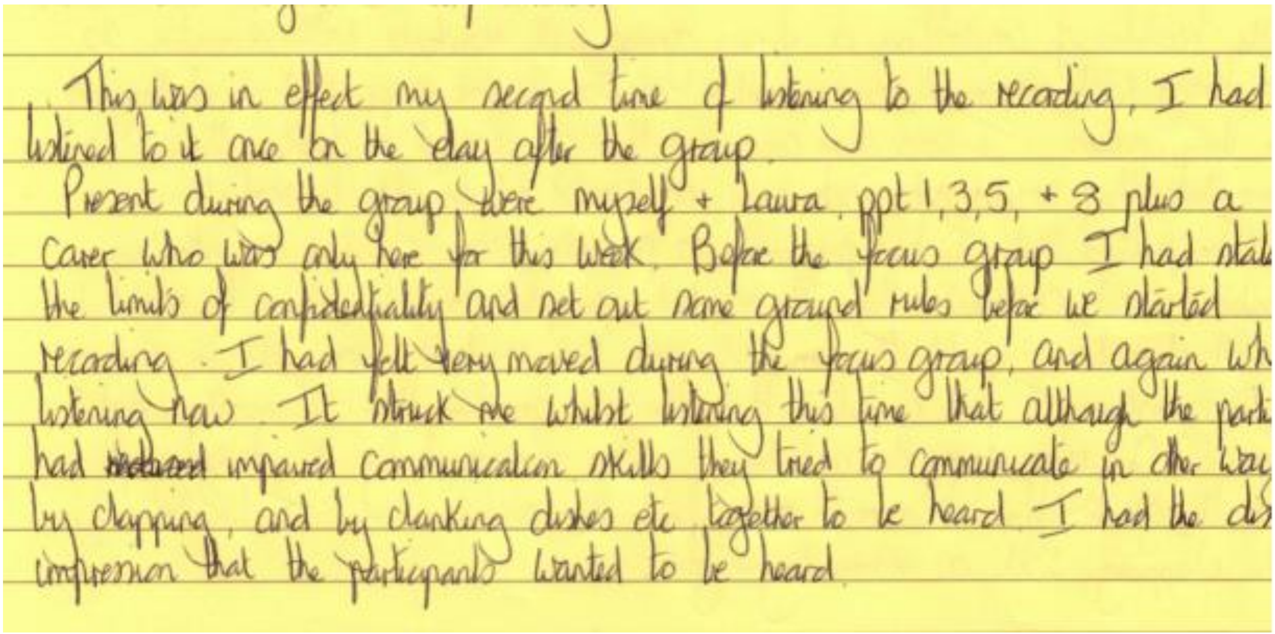
15:36-15:40: Participant 1 tastes the lemon sorbet ice cream; their facial expression is neutral but they are engaged with the activity.

15:41-15:45: The participant tastes the chocolate ice-cream and the ice-cream mix. saying 'very, very nice', and 'lovely'. The activities facilitator hands out feedback sheets while the participant sits quietly waiting.

APPENDIX 30: RESULTS OF T-TESTS COMPLETED ON THE DAS SCALE

Question	*Pre intervention Mean ±SD*	*Post Intervention Mean ±SD*	*Actual change*	*Statistical sig*	*Effect size*
1.It is rewarding to work with people who have dementia	6.75 ± 0.5	6.5 ±0.6	-0.25	.391	.50 (M)
2.I am afraid of people with dementia (R)	5.75 ± 1.25	6.5 ± 0.6	+.75	.215	.78 (M)
3. People with dementia can be creative	6.25 ± 0.5	6.75 ± 0.5	+0.50	.182	.86 (L)
4. I feel confident around people with dementia	3.75 ± 0.5	5.75 ± 1.3	+2.00	.016	2.45 (L)
5. I am comfortable touching people with dementia	5.00 ± 1.6	5.75 ± 0.5	+0.75	.319	.60 (M)
6. I feel uncomfortable being around people with dementia (R)	4.75 ± 2.8	6.25 ± 1.0	+1.5	.215	.78 (M)
8. I am not very familiar with dementia (R)	3.75 ± 2.06	4.5 ± 1.7	+.75	.58	.1.5 (L)
9. I would avoid an agitated person with dementia (R)	5.25 ± 0.9	6.0 ± 0.8	+0.75	.391	.50 (M)
10. People with dementia like having familiar things nearby	6. 00 ± 1.4	6.00 ± 1.4	000		No change
11. It is important to know the past history of people with dementia	6.25 ± 1.0	6.75 ± 0.5	+0.5	.495	.39 (S)
12. It is possible to enjoy interacting with people with dementia	6. 75 ± 0.5	6.75 ± 0.5	000		No change
13. I feel relaxed around people with dementia	5.25 ± 1.5	5.5 ± 1.3	+0.25	.789	.15
14. People with dementia can enjoy life	6.25 ± 1.0	6.75 ± 0.5	+0.5	.182	.86 (L)
15. People with dementia can feel when others are kind to them	6.5 ± 0.6	7.00 ± 0.00	+0.5	.182	.86 (L)
16. I feel frustrated because I do not know how to help people with dementia (R)	2.75 ± 1.5	4.5 ± 1.3	+1.75	.188	0.85 (L)
17. I cannot imagine taking care of someone with dementia (R)	6.25 ± 1.0	6.5 ± 0.6	+0.25	.638	.26 (S)
18. I admire the coping skills of people with dementia	6.50 ± 1.0	6.75 ± 0.5	+0.25	.391	.50 (M)
19. We can do a lot to improve the lives of people with dementia	6.50 ± 1.0	6.75 ± 0.5	+0.25	.391	.50 (M)
20. Difficult behaviours may be a form of communication for people with dementia	6.25 ± 0.9	6.75 ± 0.5	+0.5	.130	.86 (L)
Total DAS score	106.50 ± 12.50	118.00 ± 8.3	+11.50	.067	1.40 (L)
Total comfort score	49.25 ± 7.3	58.25 ± 6.1	+9.0	.020	2.25 (L)
Total knowledge score	57.25 ± 7.1	60.0 ± 3.5	+2.75	.315	0.60 (M)

APPENDIX 31: AN EXTRACT OF FOCUS GROUP FAMILIARISATION NOTES



This was in effect my second time of listening to the recording, I had
listened to it once on the day after the group.
Present during the group, were myself + Laura, ppt 1, 3, 5, + 8 plus a
carer who was only here for this week. Before the focus group I had stat
the limits of confidentiality and set out some ground rules before we started
recording. I had felt very moved during the focus group, and again wh
listening now. It struck me whilst listening this time that although the parti
had ~~reduced~~ impaired communication skills they tried to communicate in other way
by clapping, and by clanking dishes etc together to be heard. I had the dis
impression that the participants wanted to be heard.

APPENDIX 32: EXAMPLE OF FOCUS GROUP TRANSCRIPTION

Focus Group 1: Residents focus group/ Resident only intervention		
Transcript	Code	Notes
Facilitator: It’s recording now Ppt 5: carry on Researcher: ok so what we’ve done we’ve done. We did ice-cream we had the evaporated milk and sugar and we whipped it up Ppt 3: did you put something down for ….., did you? Researcher: we whipped it up Ppt 3: put something from over there down? Did you put something down for ….? Facilitator: yea Researcher: so we whipped it up to make like an ice cream Ppt 5: That was (unclear) *acceptance?* Researcher: Yea so we did an ice cream mix and then we planted some cress so we did one with uh kitchen towels and some soil and then we made a fruit salad		I laid out laminated cards of the activities here. All talking across each other here, Ppt 3 engaging in side conversation:
Ppt 3: quiet in here now Ppt 5: lovely	Showing pleasure (WB)	
Researcher : like that and then today Ppt 3: is that for you Researcher : we made a sandwich with the cress		
Ppt 5: Beautiful Ppt 3: I saw her putting it down for you	Showing pleasure (WB)	
Facilitator: yea Researcher : so could you tell me anything you liked about any of that that we did		
Ppt 5: How can I explain it now I’m not very good at explaining, the fruit salad give me good ideas which I would of never thought of to do so easy and plenty of everything fruit and so nice it was tasty Ah it was lovely with Ideal very nice	Showing pleasure (WB)/creativity	

APPENDIX 33: AMALGAMATED STUDENT WORDLISTS

Wordlist at TP1	**No of times the word was listed**	**Wordlist at TP2**	**No of times the word was listed**
Elderly person (N)	2	Strong (P)	1
Carer (Neutral)	2	Battle (N)	1
Confusion (N)	2	Memory (Neutral)	1
Frustration (N)	2	Different (Neutral)	1
Brain (Neutral)	2	Coping (P)	1
Prescriptions (Neutral)	1	Cared for (Neutral)	1
Care home (Neutral)	2	Supported (P)	1
Memory loss (N)	1	Community (P)	1
Dependency (N)	1	Hope (P)	1
Personality change (Neutral)	1	Loving environment (P)	1
Neurodegeneration (N)	1	Friendship (P)	1
Behavioural change (Neutral)	1	Chatty (P)	1
Lonely (N)	2	Sociable (P)	1
Vulnerable (N)	2	Mobile (P)	1
Care (Neutral)	1	Friendly (P)	2
In need (N)	1	Enjoys activities (P)	1
Sadness (N)	1	Memory impairments/loss (N)	1
Mood (Neutral)	1	Emotional (Neutral)	1
Support (Neutral)	1	Confused (N)	2
Change (Neutral)	1	Elderly (Neutral)	1
Behaviour (Neutral)	1	Carer (Neutral)	1
Forgetfulness (N)	1	Care home (Neutral)	1
Frustrated (N)	1	Forgetful (N)	2
Scared (N)	1	Capable (P)	1
Angry (N)	1	Guidance (Neutral)	1

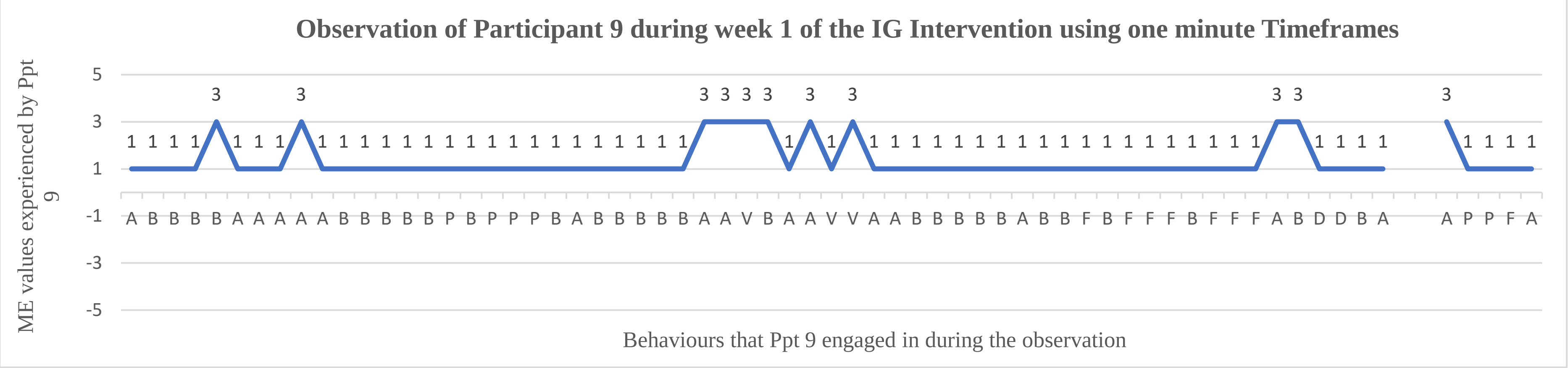
Struggling (N)	1	Memory (N)	1
Isolated (N)	1	Big personality (Neutral)	1
Anxious (N)	1	Fun (P)	1
Depressed (N)	1	Creative (P)	1
Co-dependent (Neutral)	1	Unique (Neutral)	1
		Happy (P)	1
		Sad (N)	1
		Joyful (P)	1
		An individual (Neutral)	1
Total number of words	38		37

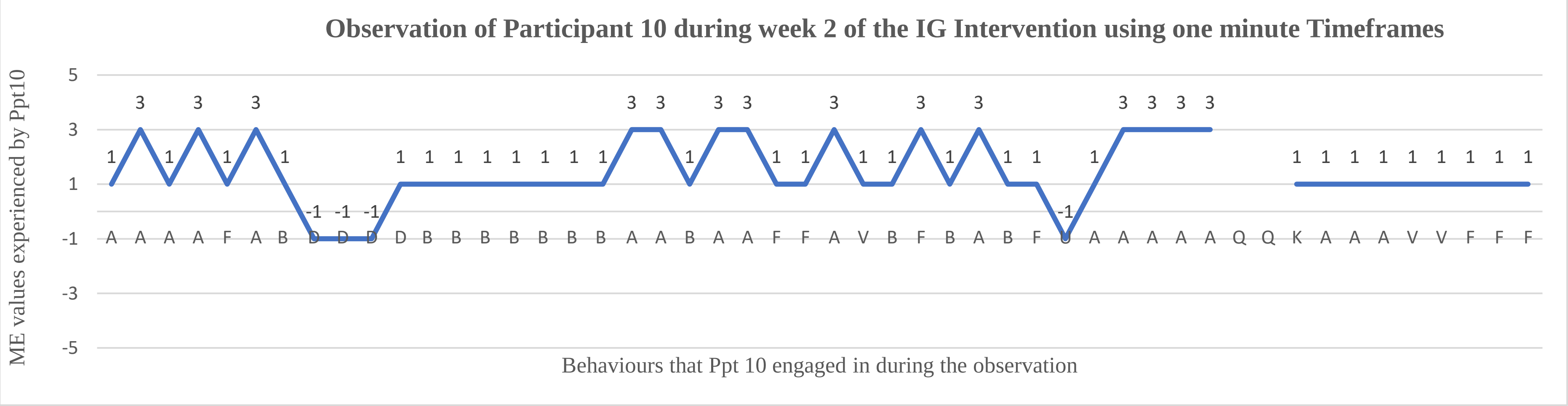
APPENDIX 34: THEMES FOUND IN AMALGAMATED STUDENT WORDLISTS

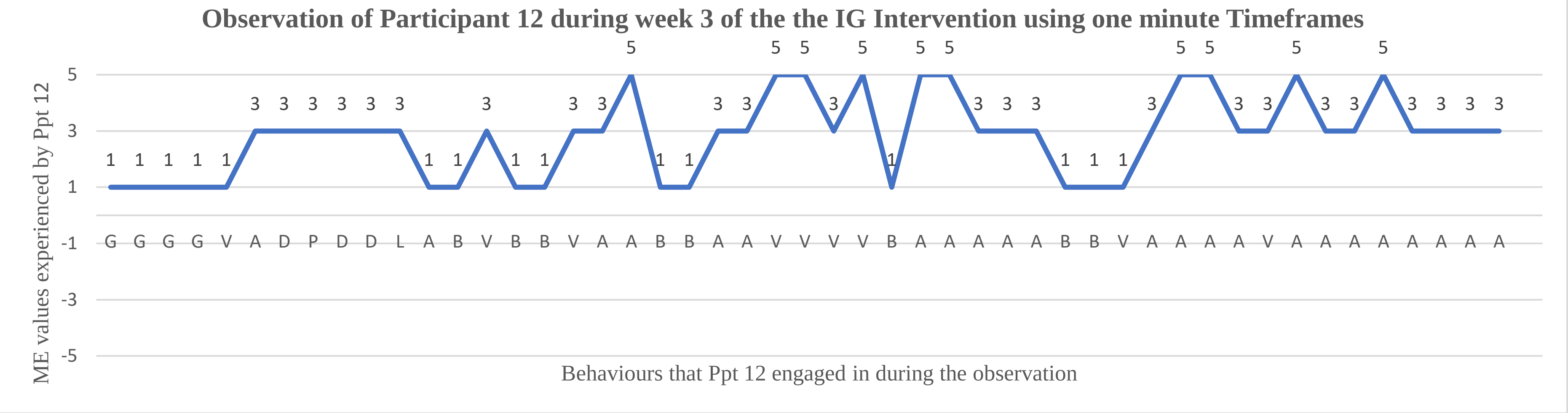
Wordlist at TP1	**Wordlist at TP2**
Theme 1: Physical	
Brain	*Strong*
Neurodegeneration	Mobile
Prescriptions	
Theme 2: Dispositional	
Personality change	Chatty
Mood	Sociable
Change	*Strong*
Behavioural change	Friendly
Behaviour	Capable
Vulnerable	Enjoys activities
	Big personality
	Creative
	Unique
	Different
	An individual
	Coping
Theme 3: Emotions	
Lonely	Happy
Frustrated	Hope
Scared	Joyful
Angry	Emotional
Anxious	

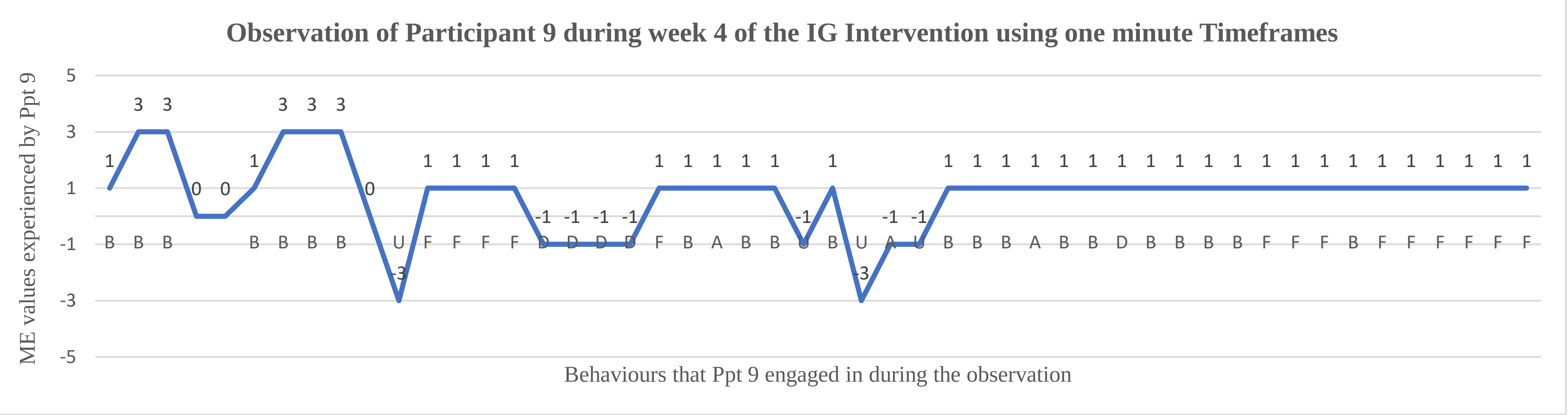
Theme 4: Situational	
Isolated	Loving environment
	Friendship
	Community
	Battle
Theme 5: Needs	
In need	Guidance
Struggling	
Co-dependent	
Dependency	

APPENDIX 35: INDIVIDUAL MAPS COMPLETED DURING THE IG INTERVENTION USING ONE-MINUTE TIMEFRAMES






Observation of Participant 12 during week 3 of the the IG Intervention using one minute Timeframes


Observation of Participant 9 during week 4 of the IG Intervention using one minute Timeframes