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The Evaluation of the Occupational Engagement Framework and its Application to People with Dementia in a Day Care Setting

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This thesis is submitted for the degree of Doctor of Philosophy

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September 2021

Abstract

Caroline Hampson

The Evaluation of the Occupational Engagement Framework and its Application to People with Dementia in a Day Care Setting

The Occupational Engagement Framework was developed by Karen Morris (2012). The framework positions occupational engagement within a framework of values and consequences, and demonstrates the relationship between participation in occupations and the relationship of this to wellbeing over time. The purpose of this research was to investigate whether the Occupational Engagement Framework was applicable to people with dementia in a day care setting.

An initial systematic literature review was completed to establish the current literature around dementia and the value and impact of occupation, which identified the importance and complexities of occupation for people with dementia. Following a hermeneutic phenomenological approach, observations and interviews were carried out with people at a specialist day care setting for people with dementia. Careful consideration was given to the inclusion of people with dementia to maximise their participation in the research process. This enabled participants to share their experiences, allowing a true understanding of their life world to be developed. Data was analysed using framework analysis, initially with the Occupational Engagement Framework as an a priori template for analysis. A second analysis of the data was completed to identify and analyse additional themes discussed by the participants.

The development of the Occupation in Dementia framework followed the second analysis. This framework re-positions the element of 'value', placing it with the occupation itself and not the participation, and proposes that occupational engagement is a spectrum of intensities which can be more positive or negative. This reflected the experiences of the participants, who identified that the value of an occupation is central to participation, engagement and consequences, being vital for supporting self and influencing a sense of wellbeing. The framework also identifies personal and occupational factors that affect whether an individual participates in an occupation and induces more positive or negative consequences accordingly.

This research further strengthens the argument of the importance of occupation to people with dementia, identifying the significance of this to self-identity, purpose in life and wellbeing. The resulting framework can be used by therapists in a day care setting to analyse participation and engagement in occupations to ensure that the best possible consequences are achieved, and wellbeing increased or maintained.

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This project would not have been possible without the help of so many people! I would like to offer firstly my sincere thanks to the staff and attendees at the day centre I visited, for making me feel so welcome and for speaking so openly to me about their experiences. Thank you to all the participants who took part in this research – it would not have been possible without you. You shared so much of your lives with me, and it was a pleasure and an honour to have worked with you.

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Finally, a huge thank you to my friends and family. To my friends: thanks for offering regular sanity checks and glasses of gin. To my parents: thank you for having faith that I could do this and for looking after the children while I studied. To my husband: thank you for your support, the cups of coffee, the technical IT support, the encouragement to keep going, and for the endless distractions!! And to my 3 beautiful, clever daughters: you are the reason I do this sort of crazy thing......you can do anything you want to if you put your mind to it. I love you all!

Declaration:

This thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Caroline Hampson

This research was supervised by Dr. Karen Morris, Dr Tom Grimwood, Dr. Alison Spurgeon-Dickson, and Alison Hampson.

This thesis is dedicated to my grandmothers, Elsie Hardie and Hilda Naylor. Both strong, independent, and influential women who stood up to dementia in their later years.

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Prologue: a little about me

Before we begin to move into the realms of this research, I just thought I would offer a little professional and personal background to help the reader understand where I began with this topic.

I qualified as an occupational therapist in 1999 and have worked in a variety of settings since that time. Over the past 21 years, I have specialised in dementia care, working with people with dementia and their carergivers to provide interventions which can support them in living well with dementia. This has included work to help them understand their diagnosis, and tailored packages to support the person with dementia and their caregivers overcome some of the challenges they may face. Latterly, this work has been from the backdrop of a diagnostic service, where my role is to assist in identifying the symptoms that a person is experiencing in order to provide an accurate diagnosis.

As a practising therapist, I have also conducted various service developments and reviews which have focussed on non-pharmacological interventions for people with dementia. This includes evaluating specialist interventions such as wellbeing groups, memory rehabilitation strategies and interventions for upskilling caregivers of people with dementia which focussed on increasing opportunities for participation in occupations and enhancing engagement so that wellbeing can be achieved. The outcome of the reviews determined that people with dementia achieve wellbeing from participating in occupations which accommodate their current limitations and provide them with successful outcomes, and that contact and support from others with a similar diagnosis is important (Hampson, 2009; Hampson, 2010). Reviews of the caregiver group was positive, with caregivers feeling more equipped with information and skills which allows them to encourage and support the person with dementia to participate and engage more fully in occupations, helping them to achieve a greater sense of wellbeing (Hampson and Smith, 2015). This current research allowed me to build on this experience and further research the experiences of people with dementia in relation to occupational engagement and to develop my own understanding of the factors which influence participation and engagement in occupations and how this influences wellbeing.

Sadly, dementia has also touched my personal life, and I have more recently been in the more helpless position of seeing loved ones develop dementia and experiencing the losses and frustrations so often expressed by those I work with professionally.

I hope that my passion for working with people with dementia is reflected in this research, and that those who read this take away the significance of hearing the voice of people with dementia and develop an understanding of the importance of supporting people with dementia to engage in occupation.

This research project was an interesting and thought-provoking experience and was a surprisingly emotional journey for me and for those who participated. Working so closely with those involved was a privilege and a pleasure and will stay with me forever.

1. Introduction: Telling the Story

> *"Stories are how we think. They are how we make meaning of life. Call them schemas, scripts, cognitive maps, mental models, metaphors, or narratives. Stories are how we explain how things work, how we make decisions, how we justify our decisions, how we persuade others, how we understand our place in the world, create our identities, and define and teach social values."*
>
> (Rutledge, 2011)

This quote sums up the importance of stories. Not only do they provide a way for us to formulate and explain ideas and decisions and situate us within our world, but they also allow us to create meaning and express our individuality. We all have our own stories to tell. A good narrative is a way of guiding people through a story to help them understand our intentions and to help them follow the 'plot'. This is the purpose of a thesis...to guide the reader through the story of the research, so that they may understand the intentions behind the research, the methods used and the outcomes. In this thesis, I attempt to tell the story of my own journey through this research and portray the thoughts and ideas that resulted from this.

The storytelling element is also essential in helping the reader to understand the lived experience of the participants. This was an important factor in the analysis of the results to ensure that the phenomenological approach to the person with dementia (and this research) captured the important elements of occupational engagement and the influencing factors for each individual.

1.1 Occupation: More than Just a Job

The word 'occupation' is often used to describe the job that people do. The primary definition of the word 'occupation' in the Oxford Dictionary is:

"A job or profession" (Oxford English Dictionary, 2018)

This is the definition that is most commonly associated with the word occupation. However, the word also means *"a way of spending time"* (Oxford Dictionary, 2018). As an occupational therapist, it is the latter definition of the word that I am concerned with, and it is this term that applies throughout this thesis.

Occupational therapy is a profession which

> *"provides practical support to empower people to facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them"*
>
> (Royal College of Occupational Therapists, 2018)

This quote from the Royal College of Occupational Therapists (RCOT) illustrates the interchangeability of the words 'activity' and 'occupation'. The indistinctness between the two terms has been debated many times over (Hinojosa and Kramer, 1997; Golledge, 1998; Pierce, 2001; Bauerschmidt and Nelson, 2011). Indeed, Carlson et al. (2014) state that there remains no one universal definition of occupation despite over 20 years of study and debate. For example, consider the following definitions which are broadly aligned with my own practice, and which demonstrate a number of crossovers and intersections:

Occupation: On a fundamental basis, occupation is essential to the existence of humans (Cox, 2017). There are some occupations which are necessary for humans to survive, for example eating, wearing appropriate clothing and having social contact with others (Reed et al., 2013). However, occupation is much more than this, and participation in occupations brings meaning and purpose to life (World Federation of Occupational Therapists, 2016). It reflects the individual characteristics and style of a person and may change over time as the personal preferences and circumstances of a person change (Hinojosa and Kramer, 1997; Golledge, 1998). Occupation may or may not present an observable physical dimension, although it draws on the mental skills and abilities of a person (Hinojosa and Kramer, 1997). Occupation often has complex personal meaning to a person, and can have any number of contextual, temporal, psychological, social, symbolic, cultural, ethnic or spiritual dimensions (Hinojosa and Kramer, 1997; Patnaude, 2021). The occupations a person engages in support the participation in individual roles e.g. teacher, parent, student, thus making them important to the sense of individuality of a person (Golledge, 1998).

Purposeful or Meaningful activity: Golledge (1998) states that there are two dimensions to purposeful activity. She states that the first level of occupation, which is purposeful and meaningful, is the same definition as occupation, and can therefore be used interchangeably. The second level is where the activity is purposeful but **not** meaningful, for example where the end result of the activity has a useful outcome, but the activity does not hold personal meaning and value to the person. Hinojosa and Kramer (1997) describe purposeful and meaningful activity as being a subset of occupation, which holds personal meaning to the person and is goal-directed i.e. the person is focussed on the outcome. With regard to people with dementia, Tierney and Beattie (2019) found that meaningful activity is highly personal, and that what constitutes a meaningful occupation to one individual may be very different to that of another. This is important for therapists working with people with dementia as participation in meaningful occupations can result in positive outcomes for the individual.

Activity: Golledge (1998) goes on to further define activity as something we do which is neither purposeful nor meaningful.

During the time spent conducting this research, participants were observed to be participating in a variety of occupations which held meaning and purpose, but were also observed carrying out activities which did not hold any personal meaning although their purpose was therapeutic in value. These definitions stress that whether the ‘thing being done’ is an occupation, a meaningful and purposeful activity, or just an activity, very much depends on the value placed upon it by the person. Understanding more about an individual helps to establish the value that a person places on an activity and therefore assists in defining whether it is an occupation, a meaningful and purposeful activity, or an activity.

Accordingly, for the purpose of this research, occupation and meaningful activity will be classed as one and the same. However, the term ‘activity’ is used to determine that the participants were involved in participating in a planned session at the centre. The reason for this is that although the sessions conducted at the centre are designed to be therapeutic and purposeful, the nature of the centre and how individuals were assigned to groups made it unclear whether this was an ‘occupation’ for the individual. Often individuals did not have a choice whether they attended the group, and although were certainly not forced to participate, they were actively encouraged to join in. It is important to recognise this at this point, so that the reader is clear about the terminology being used and to avoid further confusion.

1.2 Doing: The Importance of Occupation

> *“What I really like to do, is doing......... It’s much better than not doing. Not doing is very hard work.”*
>
> (Dinopaws, CBeebies)

The above quote is taken from a children’s TV programme and is part of a discussion between two dinosaurs about the importance of ‘doing’. I feel that it illustrates very well how important the act of ‘doing’ is, and how difficult it can be when we do nothing. The origin of the quote and the audience it was intended for also recognises that individuals are acutely aware of the importance of ‘doing’ from a young age. The word ‘doing’ can be defined as: “*the activities in which a particular person engages*” (Oxford Dictionary, 2018). The importance of activity and occupation is not to be underestimated. Perrin et al. (2008) describe occupation as

> “*That which we seize for our own personal possession, and which, because it holds meaning and value for us, habitually and fully engages our time, attention and environment.*”

(Perrin et al., 2008, p.30)

The need for occupation is deep rooted within humans and is a way in which people define themselves as well as being intrinsic to a sense of personhood and individuality (Dickens and Hampson, 2011). Additionally, Wilcock (1993) states that the need for occupation is related to health and survival. There is a powerful need within humans to remain engaged in occupations and, as demonstrated by the Dinopaws quote above, doing nothing creates such a void that people seek to create activity where none exists (Lawton, 1985; Chung, 2004). Indeed, the importance of occupation is central to occupational therapy theory, with the focus of the occupational needs and performance of an individual central to the various models of practice. As such, the literature around occupation and why it is important is extensive and well-documented, and therefore will not be discussed in great detail here. Instead, what follows will discuss the occupational impact of dementia on a person, in order to understand how the ability to participate in occupation changes as the disease progresses.

1.3 Occupation and Dementia

Dementia is a progressive illness which depletes a person’s cognitive performance. It follows therefore, that as a person’s cognition deteriorates, their ability to engage in daily occupations will change. This often leads to the person with dementia being unable to engage in occupations in a meaningful way (Hasselkus, 2001). Indeed, Perrin (1997) argues that if the need to be occupationally engaged is an innate human need, then the loss of ability to participate in occupation serves as a major unmet need in the person with dementia.

There is much research to suggest that meaningful occupation is important to a person with dementia (E.g., Qazi et al, 2010; Roach and Drummond, 2014; Roland and Chappell, 2015; Han et al., 2015; Nyman and Szymczynska, 2016; Jennings et al, 2017; Quail et al., 2021; Orgeta et al., 2021). It has been argued that there is a high correlation between engagement in valued occupations and subjective wellbeing, with particularly important occupations being described as leisure pursuits and projects which affect life, are socially valued, and allow self-expression (Furnham and Argyle, 1998; Christiansen, 2000; Pierce, 2003).

Phinney et al (2007) conducted a study to investigate what meaningful activity was to people with dementia. Through a series of interviews and observations, they concluded that through the act of *doing*, people with dementia found meaning in their lives. They found that through engaging in occupations, the person with dementia experienced pleasure and enjoyment, retained a sense of identity, and felt that they belonged to their world. Interestingly, it has been found that dementia does not have an impact on the person's perception of the importance of activity, and that activity preferences tend not to change as the dementia progresses (Kolanowski et al., 2002; Phinney et al., 2007). This indicates that regardless of impairment caused by dementia, activity and occupation remain as integral factors to the person with dementia. Egan et al. (2006) furthers this to state that occupation is very important to a person with dementia as it helps to maintain a sense of identity and can help to relieve some of the anxiety that people feel in the earlier stages of the illness. This importance of meaningful occupation to people with dementia is well illustrated, for example, by Wendy Mitchell in her online blog "Which me am I today?" (www.whichmeamItoday.wordpress.com). Diagnosed with early onset Alzheimer's in 2014, the blog is premised on the idea that keeping her mind active "shoves dementia into a corner and keeps it at bay" (Mitchell, 2017). She goes on further to describe how she believes it is important to continue being engaged in occupations because it maintains your skills and slows the pace of dementia (Mitchell, 2017). In an earlier blog, she describes how doing occupations that she enjoys (in this case gardening) provides a great deal of pleasure and generates a sense of usefulness in her (Mitchell, 2016).

Mitchell's blog describes the importance of meaningful occupation from the perspective of a person with dementia: it provides a sense of pleasure and usefulness, reinforces her sense of identity, and provides a connection with previously enjoyed occupations, and also (she feels) helps to maintain her skills and slow the progression of dementia, thus keeping her active for longer. This provides further support to the research which has been carried out in this area, but from the perspective of a person with experience.

The research conducted sought to evaluate the Occupational Engagement Framework and its application to people with dementia in a day care setting. The following chapters discuss the process of the research conducted and also the outcomes following this research with a specific focus on occupation for people with dementia in a day care setting.

2. Dementia and Occupation: Current Research

In order to establish the current literature and research around dementia and the value and impact of occupation, a literature search was completed. This was undertaken in a systematic way, using search terms to identify the literature and then a manual search through the results to ensure that they were relevant. The method used to conduct this search and the results are discussed below for clarity and transparency.

2.1 Search Method

The following method was used to search relevant literature. In the first instance, the Patient Intervention and Outcomes (PIO) method was used to help identify relevant topics and words for the search. The PIO model is one of many formats which is used to help researchers define the search question. A well-defined search question is important as it helps to form the search strategy, and guides the inclusion and exclusion criteria (Bettany-Saltikov, 2015; Butler, Hall and Copnell, 2016). The PIO method seeks to define the **P**atient, **I**ntervention and **O**utcomes which are sought to be found in the search. Figure 1 identifies the search terms which were used within the literature search. These were formed into the following search question:

What are the effects of occupation on the quality of life of adults with dementia?

Figure 1: Concepts and Topics Using PIO

Patient, Population or problem	**Intervention**	Outcome
	“Occupation”	“Engagement”
“People with dementia”		“Quality of life”
Free text		
Dementia	Occupation* Activity	Quality of life

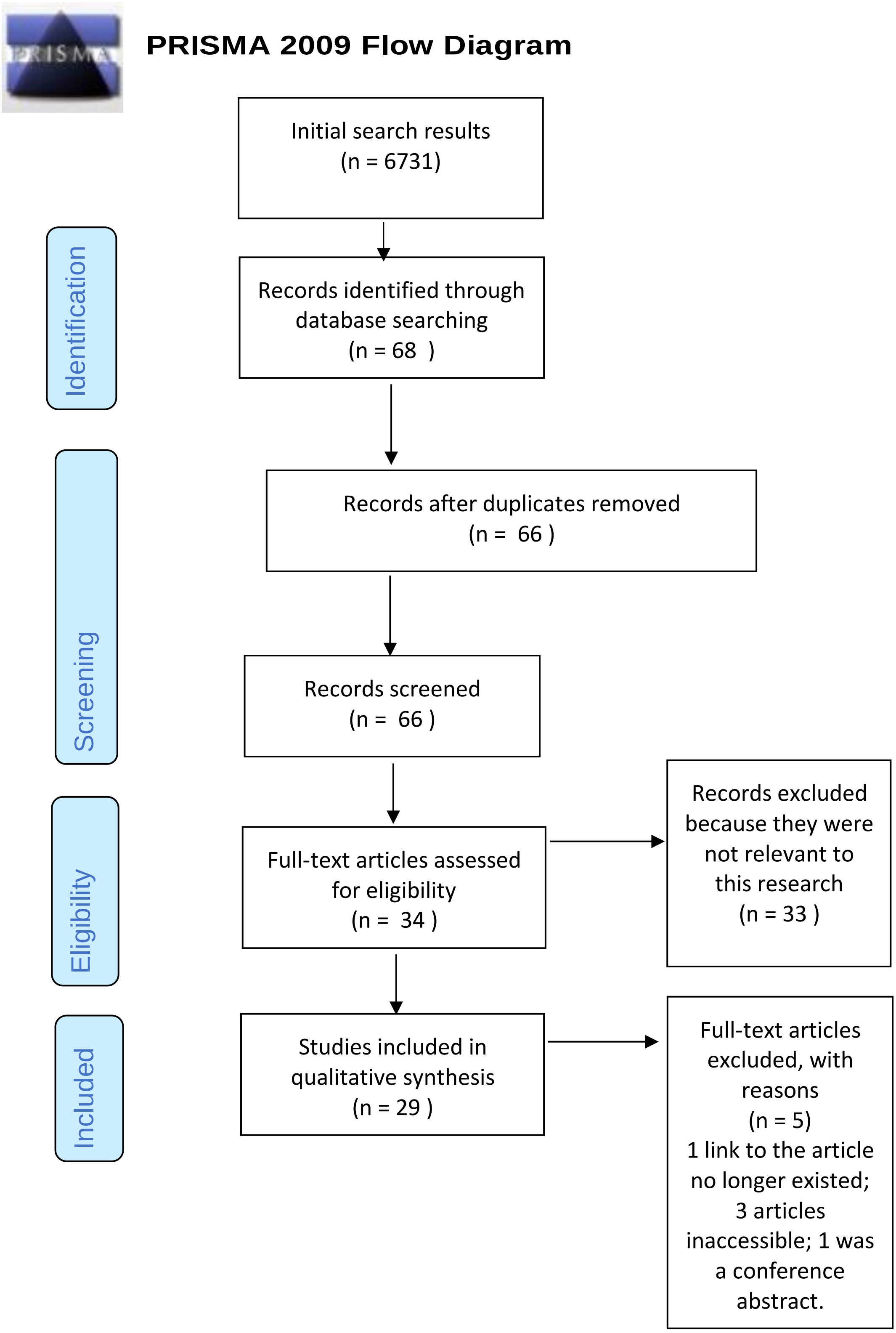
CINAHL/MeSH decriptors
dementia

MeSH is an acronym for Medical Subject Headings, and is a thesaurus produced by the National Library of Medicine which provides researchers with the terminology and descriptors for vocabulary used in biomedicine and related areas (National Library of Medicine, 2019). It is useful to ensure that the correct terms for a condition, in this case, dementia, are used in order to ensure that the relevant papers are accessed. It was decided that the term ‘dementia’ would be used rather than the sub-categories, as this would encapsulate the sub-types of dementia and would limit the results. A trial was carried out using the term “Alzheimer’s Disease” and the results produced hundreds of thousands of papers. This search identified papers which were discussing research into more complex areas of Alzheimer’s Disease, including the neurological elements of the illness, which were not felt necessary for the purpose of this research. As a result, it was decided to search for the term ‘dementia’ to reduce the number of complex medical papers produced by the previous search.

The search was completed as follows:

The initial search included the terms ‘Dementia’ AND ‘Occupation’. This yielded 279 results. This was further refined to include only results which had been published from January 2013 to the present date (August 2021) and to only include those relating to adults over the age of 44. This yielded a total of 24 results. It was felt at this stage that the search terms were too broad and were not identifying all of the relevant papers. A further search was then completed with the search terms ‘Dementia’ AND “Occupation*’. This was intended that the search would incorporate further terms such as occupational, occupations. This search yielded a total of 1290 results. The parameters of date and age were applied as per the previous search, and this resulted in 40 articles being identified. Further to this, exclusion criteria were added: NOT brain changes (2 results); NOT delirium (1 result); NOT relating to risk factors e.g., demographics, lifestyle (14 results); NOT relating to OT treatment which was not associated with this search topic (11 results); NOT relating solely to the caregiver (3 results) and NOT relating to the education of professionals (7). This gave a final result of 2 research papers. Following this, a final search was completed using the search terms ‘Dementia’ AND ‘activit*’, with the intention of incorporating the terms activities and activity. The parameters around date of publication, age of the participants and the exclusion criteria were added, and of a total of 6731 results, 68 were identified as potentially relevant to the search question. The results were then hand checked, and 35 were identified as relevant. Of these, 2 were duplicates, 1 was a conference abstract, and 4 were not accessible because the link to the paper no longer existed or because the journals did not allow access through shibboleth. This gave a total of 29 papers for consideration and were included in qualitative synthesis. Using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), the following diagram demonstrates the search process in greater detail. A PRISMA diagram is an evidence-based minimum set of items which should be used in the reporting of systematic reviews (PRISMA, 2015). These items help researchers and authors to improve their reporting of systematic reviews, making them more robust and repeatable (PRISMA, 2015).

Figure 2: Prisma Flow Diagram



The articles which were included in the review are shown in Table 1. This table includes a brief synopsis of the research. Each article was appraised using the PICo approach (Murdoch University, 2022):

P = population
I = Interest
Co = context

This approach is recommended by the Cochrane Collaboration and was evaluated as being the best approach to systematic reviews of literature (Higgins and Green, 2013; Methley et al., 2014). Using this approach helped to identify relevant research articles and evaluate their usefulness in this literature review.

Table 1: Articles identified in literature search

Author	**Title**	**Target Group/Research Participants**	**Methods**	**Summary**
Camic, P. M., Hulbert, S. and Kimmel, J. (2019)	Museum object handling: A health-promoting community-based activity for dementia care'	People with mild to moderate levels of cognitive impairment	Quasi-experimental design (*N* = 80)	The results indicated that people with early and moderate impairment showed positive increases in wellbeing, regardless of the type of dementia but those with early stage dementia showed larger positive increases in wellbeing.
Chung, P. Y. F., Ellis-Hill, C. and Coleman, P. (2017)	Supporting activity engagement by family carers at home: maintenance of agency and personhood in dementia	Resident carers of people with dementia	In-depth interviews (*N = 30*)	Findings showed that carers encouraged and sustained a sense of autonomy and control (agency) in their relative's daily activities. Key strategies used by carers included: being non-judgemental; facilitating a sense of worth; taking calculated risks; maintaining the continuity of their relative's identity; enhancing a sense of connection with their relative's role and identity using enjoyable activities; preventing inactivity and attending to the bodily source of the agency. Lack of support for carers could ultimately pose a risk to the maintenance of the agency of people with dementia.
Cornelis, E. *et al.* (2018)	A retrospective study of a multicomponent rehabilitation programme for community-dwelling persons with dementia and their caregivers'	People with dementia attending a memory rehabilitation programme and their caregivers	Pre and post-test evaluation of advanced daily living skills (*N = 30*)	The rehabilitation programme was valued by participants and caregivers, and effected significant overall improvements in the quality of life of the person with dementia and stabilised or improved behavioural disturbances.
Du Toit, S. and van der Merwe, R. (2013)	Promoting person-centred care for people with advanced dementia through environmental adaptations	Relatives of people with dementia and residents of a dementia care unit	Semi-structured questionnaires *(N = 6 realtives and 6 residents)*	This research identified that the life history (and activity preferences) of individuals in residential care should be considered along with person-specific adaptations to encourage participation in occupation

Du Toit, S. H. J. and McGrath, M. (2017)	A sense of belonging - How connectedness motivates engagement in meaningful activities for people with dementia'	People with dementia living in community or residential settings	Meta-ethnographic approach synthesising multi-ple qualitative studies with diverse study designs (*N = 34*)	Person-centred care should not merely involve activities based on people with dementia's life history. Meaningful activities in essence provide connectedness and a sense of belonging. Therefore, under-standing why activities were engaged in (e.g. was the person cycling for exercise or to be close to nature?) is key if health professionals want to promote client-directed care practices.
Melunsky, N., Crellin, N., Dudzinski, E., Orrell, M., Wenborn, J., Poland, F., Woods, B. and Charlesworth, G., (2015)	The experience of family carers attending a joint reminiscence group with people with dementia: A thematic analysis.	Family carers of people with dementia attending reminiscence groups	Semi-structured interviews (*N = 18*)	Joint reminiscence groups have the potential to provide a valuable model of peer support, however, care is required to manage participant expectations of the group and of themselves in their caring role. Increasing our knowledge in this area will help health professionals to refer carers to more suitable interventions which will hopefully increase effectiveness in supporting them within their caring role.
Garrido-Pedrosa, J., Sala, I. and Obradors, N. (2017)	Effectiveness of cognition-focused interventions in activities of daily living performance in people with dementia: A systematic review	People with dementia	Systematic review of RCTs involving cognition-focussed interventions with people with dementia	he evidence on the effectiveness of cognition-focused interventions suggests that multi-component programmes that include cognitive rehabilitation or cognitive stimulation could maintain or improve functionality in people with dementia
Gavendo, R., Blackburn, E. and Cohen-Mansfield, J. (2019)	Activity Preferences of persons with dementia: An examination of reports by formal	Family members of persons with dementia and therapeutic recreation staff involved in the	Staff and family members completed the preference assessment for each individual	Current preferences were significantly related to past preferences. Gender was also related to preference for some activities. A significant reduction in preference from the premorbid past to the present was found for music, reading, and cooking.

	and informal caregivers	care of those persons	with dementia and were asked to rate enjoyment of activities in a set programme (*N = 91*)	
Gross, S. M., Danilova, D., Vandehey, M. A., & Diekhoff, G. M. (2015)	Creativity and dementia: Does artistic activity affect well-being beyond the art class?	Residents of a care home facility who had been diagnosed with dementia	participants of a Memories in the Making programme were rated on seven domains of well-being using 18 rating scales that comprise the *Greater Cincinnati Chapter Well-Being Observation Tool©* (*N = 76)*	Staff reported no significant changes in resident well-being across the 12-week program. Interns reported significant improvements from the beginning to middle and end of the program on five well-being domains. Psychometric analyses of the *Greater Cincinnati Chapter Well-Being Observation Tool©* identified weaknesses in inter-rater reliability and found that the instrument measures two orthogonal factors – interpreted as ‘Well-Being’ and ‘Ill-Being’ – not the seven domains claimed. Quantitative evidence for the effectiveness of MIM is ambiguous, but anecdotal observations indicate that the program is beneficial for some participants, if only fleetingly.
Jøranson, N., Pedersen, I., Rokstad, A.M.M. and Ihlebaek, C. (2016)	Change in quality of life in older people with dementia participating in Paro-activity: A cluster-randomized controlled trial.	Nursing home residents with dementia	A cluster-randomized controlled trial. Ten nursing home units were randomized to robot-assisted intervention or control group (treatment as usual) (N = 53)	An effect was found among participants with severe dementia from baseline to follow-up showing stable quality of life in the intervention group compared with a decrease in the control group. The intervention explained most of the variance in change in the total scale and in the subscales describing Tension and Well-being for the group with severe dementia. The intervention group used significantly less psychotropic medication compared with the control group after end of intervention.

Keller, H.H., Martin, L.S., Dupuis, S., Reimer, H. and Genoe, R. (2015)	Strategies to support engagement and continuity of activity during mealtimes for families living with dementia; a qualitative study.	Older adults with dementia and family care partners	Longituinal qualitative study over 3 years, using individual and dyad interviews (*N = 27*)	Strategies to support quality mealtimes were devised by families as they adapted to their evolving lives. General strategies such as living in the moment, as well as strategies specific to maintaining social engagement and continuity of mealtime activities were reported.
Kielsgaard, K., Horghaden, S., Nielsen, D. and Kristensen, H.K. (2021)	Moments of meaning" Enacted narratives of occupational engagement within a dementia town	People with moderate dementia living in a Danish dementia town	Narrative in action – observations of individuals whilst participating in occupations of everyday life (N = 9)	The stories that emerged in the analysis showed how people with dementia enacted meaning through occupation. Meaningful engagement seemed to be a way for people with dementia to connect to self, others, and place. The enacted narratives display the significance for people with dementia of being able to enact their story and thus create meaning from everyday life situations. However, the process of being engaged in occupation depended on co-creation with others, who supported the enactment process by drawing on the person's occupational biography.
Lokon, E., Sauer, P.E. and Li, Y., (2019)	Activities in dementia care: A comparative assessment of activity types	Institutionalised people living with dementia	Systematic observations using the Scripps Modified Greater Cincinnati Chapter Well-Being Observational Tool (*N = 67*)	People with dementia benefit from participating in activities, regardless of the type (creative or non-creative), or who conducts them (licensed therapists or activity staff). However, in order for people with dementia to reach significantly high levels of overall well-being, it is recommend that activities are specifically designed for people with dementia and incorporate a 1:1 ratio between people with dementia and well-trained volunteers/staff members.
Mandzuk, L.L. and Sandy Bell, R.N., 2015	Therapeutic Activity Kits: A Successful Strategy For Hospitalized Patients Living With Dementia	People with dementia who were hospitalised	Pre- and post-behaviour mapping (N = 10)	Pre and post Behaviour Mapping displayed no statistically significant changes in the frequency of responsive behaviours, however during the period of time when these patients received this therapy, they remained calm, engaged in the activities, and exhibited no responsive behaviours.

Nijhof, N., Van Hoof, J., Van Rijn, H. and van Gemert-Pijnen, J.E.W.C. (2013).	The behavioural outcomes of a technology-supported leisure activity in people with dementia	Vulnerable adults with a diagnosis of dementia	Systematic review of papers published on the use of technology with people with dementia	The findings indicated the varied methodological approaches used to explore the impact of technology interventions. There was a significant lack of compelling evidence to indicate the technology intervention that is most effective. There are a wide range of devices and systems commercially available to support people living with dementia yet very little validated information to help caregivers select the most suitable technologies. Furthermore efforts to engage people living with dementia in the decision making should be expanded. Overall, the potential for technology solution to be incorporated within person-centred care provision is evident but more robust research is needed to compound these findings with people living with dementia as active participants.
O'Connor, C.M., Clemson, L., Brodaty, H., Low, L.F., Jeon, Y.H., Gitlin, L.N., Piguet, O. and Mioshi, E. (2019)	The tailored activity program (TAP) to address behavioural disturbances in frontotemporal dementia: a feasibility and pilot study.	People with dementia and their family carers	Randomised controlled trial (Tailored Activity Program: *n* = 9; Control: *n* = 11)	This study demonstrates the potential for using an activity-based intervention such as the Tailored Activity Program in frontotemporal dementia. Service providers should recognize that while people with frontotemporal dementia present with challenging issues, tailored therapies may support their function and reduce their behavioural symptoms.
O'Sullivan, G. and Hocking, C. (2013)	Translating action research into practice: seeking occupational justice for people with dementia	People living with mild to moderate dementia in the community and their primary caregiver	Interviews, observations and focus groups in the community (*N = 11*)	The participants prioritized the need to change the way dementia is perceived. Their rationale included other people's understanding of dementia and the social isolation they experience, resulting from a decline in opportunities to engage in daily activities. Occupational therapists have a significant role to play, encouraging and supporting people who live with dementia to maintain health and well-being by participating in occupations. Overcoming systemic issues that create barriers to occupation is vital.
Olsen, C. *et al.* (2019)	Engagement in elderly persons with dementia attending animal-assisted group activity'	People with dementia engaging with animal assisted activity	Analysis of videoed behaviours related to engaging with animal assisted activity (*N = 49*)	Animal assisted activity seems to create engagement in PWDs, and might be a suitable and health promoting intervention for both NH residents and participants of a day care centre. Degree of dementia should be considered when planning individual or group based AAA

Phinney, A., Dahlke, S. and Purves, B. (2013)	Shifting patterns of everyday activity in early dementia: Experiences of men and their families.	Men living with dementia and their families	Interviews and observations (*N = 7*)	Findings showed that everyday activity is not only important for supporting personhood in dementia, but it also contributes to sustaining family identity, and does so in a way that is deeply influenced by gender and masculinity.
Quail Z, Bolton L, Massey K. (2021)	Digital delivery of non-pharmacological intervention programmes for people living with dementia during the COVID-19 pandemic	A man living with dementia in the community	Mini-Mental State Examination (MMSE), Barthel's scores and qualitative observations of the therapist and carer	Adoption of technology-enabled care for people with dementia requires overcoming barriers to technology use, adaptation of therapeutic guidelines, adaptation of communication methods and carer support. Despite these challenges, therapists successfully transitioned from in-person to digital delivery of therapeutic interventions with associated benefits of continued meaningful activity reported as improvements in mood, cognition and engagement
Regier, N.G., Hodgson, N.A. and Gitlin, L.N. (2017)	Characteristics of activities for persons with dementia at the mild, moderate, and severe stages	Families involved in the TAP (Tailored Activity Programme) trial	Secondary data analysis of activity prescriptions or written documents detailing prescribed activities, cueing needs, and engagement goals designed by occupational therapists (*N = 58)*	Type of activity, recommended cueing, and engagement time differed by dementia stage. Findings provide guidance as to how to use and set up activities across the dementia trajectory
Roland, K. P. and Chappell, N. L. (2015)	Meaningful Activity for Persons With Dementia: Family	Family caregivers of people with dementia	Interviews with caregivers (*N = 906*)	Findings highlighted the importance of activity for both caregivers and PWDs as well as the need to support caregivers to enable PWDs to continue to participate in meaningful activity, improving QoL of both. The positive effects of activity related to promoting individual interests and providing targeted support for both PWDs and caregivers. Supporting activity participation may

	Caregiver Perspectives			be effective in improving PWD sense of self, daily functioning, and improve the well-being of the caregiver.
Stav, W.B., Hallenen, T., Lane, J. and Arbesman, M. (2012)	Systematic Review of Occupational Engagement and Health Outcomes Among Community-Dwelling Older Adults	Systematic review of existing evidence for the health benefits of engagement in occupations and activities among older adults	98 articles	The results of this review demonstrate the multidisciplinary appreciation for occupational engagement and associated well-being and elucidate the health effects of engagement in a wide variety of occupations and activities. Additionally, the results of this systematic review support occupational therapy's historical ideologies and core philosophies linking occupational engagement to improved health and well-being.
Strick, K., Abbott, R., Thompson Coon, J., and Garside, R. (2020)	Meta-ethnography of the purpose of meaningful occupation for people living with dementia	People with dementia	Meta-ethnography of qualitative studies relating to meaningful occupation for people living with dementia (*N = 6*)	The researchers found that the fundamental purpose of occupation is to support the person living with dementia to feel they are living a meaningful and fulfilling life. Three overlapping concepts were identified: (i) catalytic environment, (ii) meaningful life and (iii) occupation as a tool. A framework was proposed which suggests how occupation could support meaning in multiple ways and considers how these forms of meaning were influenced by the worldviews and values of the individual, and context in which they were experienced.
Tatzer, V.C. (2019)	Narratives-in-action of people with moderate to severe dementia in long-term care: Understanding the link between occupation and identity	People with dementia living in long term care facilities and their carers	Narrative analysis based on a narrative-in-action approach, using observations, interviews and informal talks whilst doing occupations (*N = 4 people with dementia and 4 caregivers*)	This study identifies the transactions of identity and sense of self, occupation and narrative even in people with advanced dementia. The participants used narrative elements and meaningful occupations to maintain and construct aspects of their identities, even those with high levels of cognitive impairment and problems with verbal communication in the restrictive environment of the long term care facility

Tierney, L. and Beattie, E. (2020)	Enjoyable, engaging and individualised: A concept analysis of meaningful activity for older adults with dementia	Papers which focus on meaningful activity	Walker and Avant's method of concept analysis applied to papers concerned with ‘meaningful activity’)*N = 29*)	A conceptual model was created which identified five attributes that make activities meaningful for people with dementia: (a) enjoyable; (b) suited to the individual's skills, abilities and preferences; (c) related to personally relevant goals; (d) engaging; and (e) related to an aspect of identity. This illustrates how individual and opportunity factors influence participation in “meaningful activity” and the consequences of this participation as discussed in the existing literature.
Trahan, M.A., Kuo, J., Carlson, M.C. and Gitlin, L.N. (2014)	A systematic review of strategies to foster activity engagement in persons with dementia	Studies focusing on modifications of meaningful activities with people with dementia, which used an outcome measure to determine effect	Systematic review of studies involving 50 tests of different ways of modifying activities to enhance engagement and reduce behavioural and psychological symptoms for this group (*N = 28*)	The review revealed a growing evidentiary base for different modifications to foster engagement in activities and reduce behavioural and psychological symptoms of dementia.
Travers, C. *et al.* (2016)	Effectiveness of meaningful occupation interventions for people living with dementia in residential aged care: a systematic review’	People with dementia living in residential homes	Systematic review of published and un-published studies (*N = 34*)	Providing meaningful or individualized tailored activities for people with dementia living in residential care appears to be effective for a range of behavioural and psychological symptoms. The strongest evidence was for individualized activities/recreational interventions for a range of behavioural, psychological symptoms of dementia; preferred music for agitation, depression and anxiety; and RT for mood and cognitive functioning.

Woods, B., Aguirre, E., Spector, A.E. and Orrell, M. (2012)	Cognitive stimulation to improve cognitive functioning in people with dementia	People with dementia undergoing cognitive stimulation	Cochrane review of randomised controlled trials (RCTs) of cognitive stimulation for dementia which incorporated a measure of cognitive change (*N = 15 RCTs)*	The review found that there is consistent evidence from multiple trials that cognitive stimulation programmes benefit cognition in people with mild to moderate dementia over and above any medication effects. However, the trials were of variable quality with small sample sizes and only limited details of the randomisation method were apparent in a number of the trials

2.2 Occupation and Dementia: Value and Effects

The literature search returned papers which focussed on the value and effects of occupation for people with dementia. This focus aligns with the research conducted here, as it helps to define and identify the consequences of participation in occupations and begins to help formulate thoughts about the consequences which occur as a direct result of participation in occupations. Nijhof et al. (2013) stated that people with dementia have a “need for company, daytime activities, self-worth, expression of thoughts, social contact and a sense of belonging” (p. 263). This not only identifies that occupations (i.e., daytime activities) are essential for people with dementia, but also indicates that people with dementia need to feel a sense of worth and belonging (which support self-identity) and also that interactions with others are essential. This was further supported by Kielsgaard et al. (2021), who found that people with dementia connect to self, others, and place through engagement in meaningful occupation. In keeping with this, this research further demonstrates the need for participation in occupations and the importance of these in supporting self-identity. The research is conducted within a day care setting, which for many of the participants fulfils the need for social contact with others.

Further supporting the importance of occupation, O’Sullivan and Hocking (2013) argued that the occupational deprivation (i.e., the loss of occupation) that is experienced by people with dementia is a complex issue. They stated that dementia causes a loss of participation in occupation by the very nature of the illness, and that the loss of occupation also exacerbates the symptoms and effects of dementia on a personal and social level. Furthermore, they argue that the preservation of occupation can help a person with dementia remain well physically and retain a sense of well-being, which is much in line with previous theories around the rementing process and the benefits of supporting personhood for a person with dementia (Kitwood, 1997; Sixsmith et al., 1993; O’Sullivan and Hocking, 2013). The decline in cognitive ability can be frustrating, and cause withdrawal from daily activities which has a significant impact on wellbeing (O’Sullivan and Hocking, 2013). Fundamentally, meaningful occupation supports the identity of people with dementia and enables them to feel that they are living a meaningful and fulfilling life (Tatzer, 2019; Strick et al., 2020). This highlights the importance of participation in occupations for people with dementia, not only for the preservation of function, but also for the individual to maintain a sense of wellbeing, self-identity, and connectedness with their lifeworld.

The importance of occupation to the sense of self (or personhood) of a person with dementia was also found in the research of Phinney et al. (2013). Their research found that being unable to successfully participate in occupations which once defined the individual resulted in a sense of loss and absence for a person with dementia. This created a sense of emptiness and lack of achievement which in turn led to a loss of passion, commitment, and enthusiasm for other activities (Phinney et al., 2013). While this sense of loss was devastating for the person with dementia and their families, Phinney et al. (2013) discovered that a drive to continue to be engaged in the world remained, and people with dementia and their families found different roles and activities which allowed them to maintain a sense of personhood. This further demonstrates the continuing desire to remain occupied and the importance of this to the sense of self (or personhood) of the person with dementia. The link between personhood and participation in meaningful activity is explicit in a person with dementia as they continue to define themselves by the things they do (Phinney et al., 2013). The influence of the caregiver is often central to the participation of a person with dementia in meaningful and engaging activities (Keller et al., 2015; Regier et al., 2017). Caregivers have been found to be innovative in their ways of adapting activities not only to maintain engagement in valued activities, but also to maintain dignity, nurture relationships and to maintain a sense of personhood for the person with dementia (Keller et al., 2015). This places the caregiver in an important position with regard to occupations for the person with dementia.

The above research describes the importance of occupation to people with dementia. It is central to self-identity, wellbeing, and maintenance of skills and when faced with a loss of opportunity to participate in previously valued occupations, individuals will seek out occupations to reduce this loss and to help maintain personhood. This then places value on the occupations to the person with dementia. The notion of occupations being valuable is further supported by the findings of Trahan and Carlson (2014), who discovered that activities which were tailored to the interests and abilities of people with dementia had a positive effect on behavioural symptoms, suggesting that these activities were more engaging. Similarly, Mandzuk and Bell (2015) evaluated the use of personalised therapeutic activity kits on the behaviour of in-patients with dementia. While they found that the activity kits did not demonstrate a reduction in responsive behaviours, they did find that there was a positive response from patients as they were more engaged, calmer, and showed interest in the activities (Mandzuk and Bell, 2015). This suggests that engaging people with dementia in activities which held meaning for them has a positive effect on the general wellbeing of the individual. An understanding of what gives an activity meaning is often gained from the individual’s personal history, preferences, and current level of skill, all of which should be considered so that the benefits of the activity are optimised (Melunsky, 2015). Personal history can be especially important in ensuring that activities hold meaning for the person: activities which held meaning and value in the past for the person may once again hold meaning as more recent memory diminishes (du Toit and Merwe, 2013). Chung et al. (2017) found that using knowledge of the person’s history, preferences, current skills, and abilities and needs to adapt activities can make those activities more engaging and reaffirm the person’s sense of agency and personhood.

Whilst the benefit of participation in occupations which hold personal meaning and value has been shown to be positive, Cohen-Mansfield (2019) provided a word of caution. She stated that that while previous studies have demonstrated that activities which are linked to premorbid interests are more engaging, the value of these activities can change as dementia progresses with individuals finding previous past-times less engaging (Cohen-Mansfield, 2019). It was also identified that there can be difficulty in distinguishing activities which hold value and meaning for the person with dementia as they may not be able to communicate this and carers and family members cannot always accurately identify engaging activities (Cohen-Mansfield, 2019). This suggests that therapists should remain mindful when trying to identify suitable activities for people with dementia: whilst previously valued occupations may continue to provide some positive consequences, the loss of ability as the symptoms of dementia progress mean that the value of the occupation may change and it may become less engaging. This challenges the therapist to help the individual identify new occupations which hold similar value, and which support the personhood of the person with dementia in order to maintain a sense of wellbeing.

The work of Roland and Chappell (2015) may offer some further insight into the value of occupations and how people with dementia participate in these. They argue that the value of activities and outcomes may change as the dementia progresses. In the earlier stages of dementia, a person may experience more negative outcomes such as anxiety, disinterest, fatigue, and confusion, leading to diminished participation in activities as they become less engaging (Roland and Chappell, 2015). Conversely, in the moderate to severe stages, activities which are more engaging might provide an increased opportunity for social interaction, preserve functional abilities, and increase satisfaction (Roland and Chappell, 2015). Regier et al. (2017) furthered this argument: they state that meaningful activities can remain engaging regardless of the stage of dementia so long as they are graded appropriately, and the correct support offered to encourage and maintain participation. They also argue that diurnal considerations may be important in addition to the person’s stage of dementia (and therefore level of impairment), so that the activity is performed when their function is at an optimum level for the task e.g., more complex cognitive activities earlier in the day, physical activities in the afternoon, and more sensory activities later in the day (Regier et al. 2017).

In addition to the centrality of occupation to the sense of self of people with dementia, and the importance of participation in valued occupations, researchers also considered the consequences of participation in occupation. The common finding among the studies was that occupations which were deemed engaging for individuals provided a greater sense of wellbeing and improved quality of life for the person with dementia. Activities which people with dementia find engaging can result in an improved quality of life, increased pleasure and enjoyment, increased animation, greater social interaction and conversation, engagement and concentration on the task, and a sense of achievement (Jøranson et al., 2016; O'Connor et al., 2019). This positive outcome has the potential to impact on the quality of life of the person with dementia and help to alleviate the negative symptoms of dementia e.g., psychological and behavioural changes (O'Connor et al., 2019). However, it is important to note that these activities should be *meaningful* for the person to experience an improved sense of wellbeing.

Gross et al. (2016) investigated the origins of the quality-of-life descriptors for people with dementia. They state that these factors are situated within activity theory (Bedny & Meister, 1997; Engestrom et al., 1999), which suggests that increased psychological wellbeing and better quality of life are achieved by the individual being engaged in the world around them (Gross et al., 2016). Furthermore, Gross et al. (2016) stated that people with dementia often experience a loss in their communication skills, which limits their interactions with others and the world around, thus decreasing their quality of life and negatively affecting their psychological wellbeing. They proposed that creative activities allow the person with dementia to communicate in a different way, and therefore this increases their opportunity for wellbeing and increased quality of life. However, Gross et al., (2016) advised that it was difficult to establish an objective effect on wellbeing and quality of life, adding that subjective, anecdotal, and observational evidence was the most effective way of determining the outcomes of the activity. This further supports the methodological approach taken within this research. If an individual's connectedness to the world in which they live is crucial to their sense of wellbeing, it follows that we should explore the experiences of those individuals in order to understand it more fully and to explore the occupations that enhance this connectedness and which provide a greater sense of wellbeing so that these occupations can be encouraged and adapted in order to allow the person with dementia to continue participating and engaging with these. The work by

Gross et al. (2016) also provides support for investigating the experiences of the participants of this research by exploring their subjective experiences and observing them in the world they inhabit (in this case a day centre) to fully understand their lived world. The hermeneutic phenomenological approach used in this research aims to reflect the experiences of the participants in relation to occupation in order to understand the relationship of this to the Occupational Engagement Framework proposed by Morris (2012).

Some of the research identified focussed on particular activities and evaluated the outcomes of these for people with dementia. Lokon et al. (2019) argue that engagement in creative activities has a positive effect on people with dementia physically, emotionally, psychologically, and behaviourally. However, they found that *any* engaging activity had a positive effect on wellbeing although non-creative activities elicited less social interaction (Lokon et al., 2019). Nijhof et al (2013) conducted a study to investigate the usefulness of technology in reminiscence with people with dementia. Whilst their study did not find a statistical difference between the technology and non-technology groups, they did find that that reminiscence encouraged social behaviour for people with dementia. This study defined social behaviours as: positive verbal interactions (conversation, yes/no answers, responses to stories, asking questions, joking, singing); positive non-verbal behaviours (laughing, smiling, gesturing); negative non-verbal behaviour (observing/listening, sitting alone/not observing, sleeping, wandering, leaving an activity, handling objects); and negative verbal behaviour (complaints, screaming/yelling, talking to self) (Nijhof et al., 2013). They found that women and those with greater cognitive abilities demonstrated greater positive verbal and nonverbal interactions than those who were more cognitively impaired, and that some people were naturally more talkative than others (Nijhof et al., 2013). Overall, this study demonstrated that reminiscence allows a person with dementia to recall their own experiences and that this creates in positive verbal and non-verbal social behaviours, thus increasing the quality of life for that person (Nijhof et al., 2013).

Whilst the focus on particular activities might be useful for therapists and for centres which focus on encouraging participation in activities (such as the centre visited in this research), it is the outcomes of this research rather than the activity focus which are most useful. These correlate with research into occupations generally, finding that quality of life is improved when people with dementia participate in occupations which support identity, self-expression, and social interaction, returning us to the work of Nijhof et al. (2013) and reinforcing the importance of participation in occupations for people with dementia.

In addition to the consideration of post participatory effects of occupation, Camic et al. (2017) explored the importance of “in-the-moment wellbeing” (p. 3). They state that this is the subjective wellbeing of a person with dementia in a given moment in time, and that understanding this can provide an insight into which activities will provide a sense of ‘in-the-moment wellbeing’ (Camic et al., 2017). This theory was elicited from studies which found that activities (or occupations) which provide cognitive stimulation, are creative, provide emotional stimulation and are appropriately challenging, but which do not rely on previous memories (i.e., reminiscence or previous knowledge) (Basting, 2009; Woods et al., 2012). If the balance is not correct, this can cause significant distress to a person with dementia, thus promoting a sense of ill-being (Woods et al., 2012; Camic et al., 2017). This demonstrates the immediate feedback from an occupation, and the importance of the selection of appropriate occupations for the person with dementia to participate in. In combination with the previous research findings presented above, this adds to the complexities of occupation for people with dementia and demonstrates the importance of careful choice of occupations to ensure that they are valued, provide adequate stimulation cognitively and socially, are not overchallenging and that they support the identity of the individual in order to elicit a sense of wellbeing and quality of life.

The literature search not only clearly demonstrates the importance of occupation to people with dementia, but also highlights the complexities of this and the challenges that dementia presents when individuals wish to remain engaged in occupation. Occupation is not only essential for wellbeing, but also self-identity and quality of life, and therefore as occupational therapists it is important to develop an understanding of the factors which influence occupational engagement and to discover ways of overcoming challenges which may present for people with dementia. This research explores the subjective experiences of the participants to establish if the Occupational Engagement Framework (Morris, 2012) is applicable, considering the complexities of occupation within the context of dementia where self-identity and abilities are challenged by deteriorating cognitive function. The following chapter provides a critical evaluation of the Occupational Engagement Framework (Morris, 2012) in order to begin to understand the appropriateness of this within a dementia care setting.

3. Critical Analysis of the Occupational Engagement Framework

The research in this thesis was concerned with evaluating the proposed Occupational Engagement Framework (Morris, 2012) in a dementia care setting, to establish if the framework is transferrable to this area and to determine whether any adaptations are required. The research conducted at that time sought to define the term ‘occupational engagement’, as there was no previous consensus as to the specifics of this term. ‘Occupational engagement’ is a term used with the fields of occupational therapy and occupational science, but which lacks a clear and succinct definition within the literature (Morris and Cox, 2017). This chapter seeks to provide an introduction to the Occupational Engagement Framework, and to begin to develop an analysis of the framework so that this can be applied to the data obtained in this research in order to test whether it is applicable to people with dementia in a day centre setting, and to establish if further development of the framework is required to make it more meaningful and accessible in this setting.

3.1 Summary of the Occupational Engagement Framework

In order to increase the reader’s understanding of the framework, a summary of the research completed by Morris (2012) is provided, along with a description of the final proposed framework. It is important to establish the purpose and function of the Framework in order to determine its usefulness to the setting used in this research.

In order to explore what ‘occupational engagement’ is, Morris gathered the stories of five men living in a regional secure unit. The stories were comprised of interviews, observations and records from the unit, and the aim was to develop an understanding of how their participation in occupations evolved over a 12-month period. A social constructionist methodology along with the principles of heuristic analysis were used to conduct the research and analyse the data (Burr, 2003; Moustakas, 1990). This approach allowed the theory to emerge from the data itself, rather than being influenced by previous theories and ideas.

As a part of the research, Morris (2012) completed an extensive literature review and found many differing definitions of the term, ranging from it being something which is objective, observable, and therefore measurable, to being more of a subjective ‘construct’ (i.e., a conceptual idea and not based on empirical evidence) (Morris and Cox, 2017).

Following an extensive period of submersion in the data, a definition of the term ‘occupational engagement’ emerged:

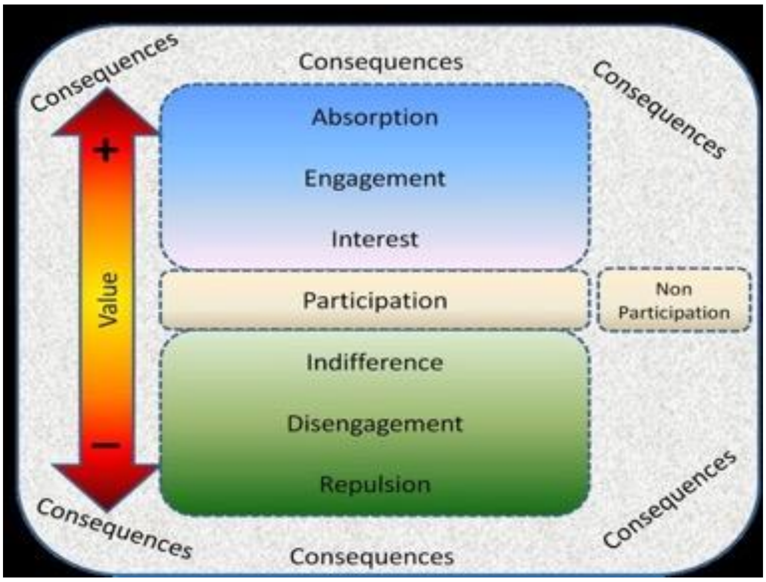
> *Occupational engagement is positioned within a framework of personal value and perceived consequences to participation. Occupational engagement is the involvement in an occupation with current positive personal value attached to it. Engaging occupations require more involvement than those occupations that just interest the individual, but not as much as those that absorb them. Occupational engagement is a fluctuating state influenced by complex and multiple internal and external factors. The person will perceive positive or negative consequences to participation, which may change over time in response to feedback from social, cultural, and physical environments. Positive wellbeing occurs when people participate in occupations with both positive personal value and positive perceived consequences for both the individual and the society in which they live.*
>
> *(Morris and Cox, 2017, p.9)*

This description states that to achieve occupational engagement, the occupation must hold a personal value to the individual concerned. Morris identified seven possible values of occupation, and the value of the occupation changed according to the many internal and external factors which influence a person. As a result of participation in an occupation, an individual will experience consequences, and the actual or perceived consequences may change according to the feedback the person receives. Morris and Cox (2017) conclude by surmising that participation in occupations with a higher value and which promote perceived positive consequences results in an increase in wellbeing of the individual. The word ‘perceived’ is integral to this, as it is what the *individual* recognises as positive and valuable, which may be different from those around them.

In terms of therapy, this understanding is relevant as it helps therapists to understand the importance of occupational engagement, helps to understand the motivating factors which influence participation, and it also helps to identify that occupations have differing values to the individual.

In addition to the description, Morris (2012) devised a framework to demonstrate the different values which a person may experience whilst participating in an occupation. This is shown in Figure 3. The visual depiction of the Occupational Engagement Framework demonstrates that participation is the “*anchor and entry point into the framework*” (Morris and Cox, 2017 p.8). This was portrayed in this way because non-participation cannot be considered to be an occupation as the person is not active (Morris and Cox, 2017). The framework demonstrates the varying values of occupation that were identified by Morris in her research and ascribes a hierarchy to them in that they are increasingly positive or increasingly negative. The framework does not attempt to quantify the consequences or state whether more positively valued occupations lead to more positive outcomes and vice versa, as it was found that there was a great variance in this: the perceived consequences of participating in an occupation with positive value may not necessarily lead to more positively perceived consequences. Morris and Cox (2017) give the following examples: a young person may find experimenting with recreational drugs an interesting occupation, and this may produce perceived positive consequences with the effects of the drugs, but if they are caught by parents may produce negatively perceived consequences by them being grounded. Conversely, a younger person may find a boring revision session a more disengaging occupation, but participation may produce more positive consequences by achieving a higher grade in the exams.

Figure 3: A descriptive framework positioning occupational engagement within other values

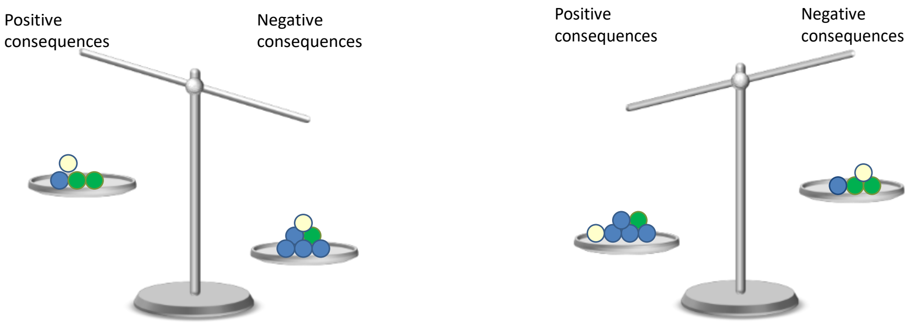


(Morris, 2012)

The framework image above depicts the identified values as levels: Interest, Engagement and Absorption represent graded levels of positive value. (i.e., engaging occupations hold more value than those that interest, but not as much as those that absorb the individual). At the other end of the continuum representing negative values are: Indifference, Disengagement and Repulsion (Morris and Ward, 2018).

In order to demonstrate the balance of occupations and the impact of these on the wellbeing of a person, Morris (2012) depicted the occupations as weights on a weighing scale, as seen in Figure 4 below:

Figure 4: The Balance of Occupation



Key:

Blue sphere = positive value

Green sphere = negative value

Beige sphere = neutral value – participation or non-participation

The image of the scales in Figure 4 demonstrates that if people participate in more occupations with a positive value, the scales will be tipped more favourably than if they were engaged in more occupations with a negative value.

Morris (2012) situated the results within the occupational therapy models used at that time in order to make the framework applicable to practice. Morris (2012) claimed that the Occupational Engagement Framework could be situated alongside any of the current models of practice within occupational therapy, and indeed would provide a useful link between theory and occupational analysis tools used in practice.

Morris (2012) also stated that the framework provides a reminder to therapists about the importance of the value of the occupations to their service users, and the need for frequent re-evaluation of this over the duration of the treatment to ensure that valued and meaningful occupation remains central to the therapists' interventions.

3.2 Analysis

There is very little evidence of critical review of the Occupational Engagement Framework, with the only papers written on this being partially authored by Morris herself. The original paper written by Morris describes an evaluation of the framework by the authors and therapists working in two secure residential units, and focused on the application of the framework to the development of a therapeutic tool (Morris and Ward, 2018). A tool was developed but because of time restrictions a full evaluation was not possible, however generally it was reported that the occupational engagement framework had "potential for increasing the understanding of the relationship between the value and consequences of participating in occupations" (Morris and Ward, 2018). This demonstrates that therapists in the secure units found that there was a potential for using the framework, but no robust tools were developed as a result.

While the feedback from Morris reports that the framework has been well-received, there is little proven evidence that it has applications to occupational therapy practice, and no evidence that it is applicable to any other area of occupational therapy practice. While Morris surmises that the framework is applicable to all occupational therapy models of practice and can be used alongside the activity and occupational analysis tools used in practice, there has been no research conducted to prove or disprove this.

As a therapist, the development of the framework is a very interesting prospect: the concept of a framework which defines occupational engagement, and which potentially aligns with any model or assessment tool used within therapy is an exciting idea. It would help therapists to plan and evaluate their treatment plans and interventions and would provide a basis on which to explain the uses of occupation as treatment to service users, carers, and other professionals, rather than using terminology which is inaccessible to anyone outside of the profession.

However, there are elements of the framework which, in my opinion, require further thought and development. Firstly, an evaluation of the application of the framework to a population outside of secure services would be beneficial. This would help to prove or disprove the supposition that the framework is applicable to all areas of occupational therapy. Secure services form a very specialised and narrow field within occupational therapy, and therefore the framework may only be applicable in this area. Secondly, the illustration of the framework for me is not detailed enough to show the intricacies and interrelationships of the values and the consequences, which potentially creates a barrier to therapists using the framework. Thirdly, the language used within the framework may be open to interpretation: what one therapist or service user defines as 'engaging' may not be the same as another (although considering that the value is that of the individual involved in that occupation, this may not be of consequence). And finally, the depiction of the weighing scales may not be the most effective way of demonstrating the effects of participation in occupations with varying values and consequences.

While Morris has completed a thorough analysis of the data produced by her research and developed a potentially useful tool for therapists to use in their daily practice, further research is now required to establish its application to other areas of practice and to discover if further development of the final framework will increase the impact and usefulness within interventions.

3.3 Summary

Having established that the Occupational Engagement Framework is potentially useful for therapists, and that further investigation and development may increase the impact and feasibility for use in wider areas of practice, it is proposed that the framework is initially tested in a population that is different to that of a secure residential unit. Therefore, this research seeks to apply the framework to people with a diagnosis of dementia who are attending a day care centre. It is anticipated that this will discover the application of the framework to another area of practice, and will also allow the development of the framework further in order to increase the usefulness to therapists in their interventions.

Image created by Peter

4. Methodology and Ethics: Considerations, Perceptions and Choices

This section explains my own approach to people with dementia and explores how this relates to the methodology of the research, the methods which were chosen and the ethical considerations that this entailed.

As a professional working within dementia care, the approach towards the person with dementia is important. Not only does this define the treatment that a person receives, but it also determines how you approach the individual. Hughes (2014a, p.89) states that “it is striking how philosophical thought leads us in the direction of physical acts”, meaning that our own thoughts and beliefs about any particular ‘thing’ defines how we relate to those things and the actions we take towards them. In terms of dementia care, the medical model approach to care would be to focus on and treat the illness itself, taking little account of the person. In social and health care, the focus in recent years has been one which places more emphasis on the individual and not the illness. This approach places the person at the centre of their care and focuses on improving quality of life and promoting the notion of ‘living well with dementia’.

This is an approach which has been promoted by policy makers, people with dementia and their advocates for many years. Indeed, a search of the term ‘dementia’ on www.gov.uk, the UK government website (accessed on 25th August 2021), returned 879 policies, speeches, news stories, and guidance on providing the best care for people with a diagnosis of dementia. The main driver in this wide-ranging literature is that people with dementia should be at the centre of their care and should be encouraged and assisted to live life well with their diagnosis. This approach to care is called ‘Person Centred Dementia Care’, and was an approach developed by Tom Kitwood, who was a member of the Bradford Dementia Group. He first outlined the principles of this approach to dementia care in the 1980s, with his book ‘Dementia Reconsidered: The Person Comes First’ being published in the UK in 1997.   At a similar time, Steven Sabat was developing a comparable approach in the USA. Sabat’s perspective sought to support the ‘selfhood’ of the person with dementia by focusing on the person and their life history, rather than focusing on the illness itself (1994; 1999; 2001)[1]. An in-depth examination of the notion of self and dementia was completed as a part of this research and can be found in Appendix 1. In addition, reading was completed around the construct of dementia, to examine the biological, social, and political positioning of people with dementia in order to develop a deeper understanding of the need for the person-centred approach to care. This can be found in Appendix 2.

The approaches used by both Kitwood and Sabat are founded within phenomenology, although Sabat's proposed model of care is based within social constructionism, a denomination of phenomenology which focuses on psychosocial interactions, and which shaped the design of this research (Hughes, 2014a).

Phenomenology is concerned with describing and analysing phenomena (Emiliussen et al., 2021). It is defined as:

> *"The study of lived human phenomena which occur in every day social contexts in which the phenomena occur, from the perspective of those who experience them"*
>
> (Titchen and Hobson, 2011, p121-122)

This research embraces a phenomenological approach in order to facilitate the person with dementia in the research process and also to enable their experiences to be heard and understood.

There are many perspectives within phenomenology, but generally speaking it addresses the everyday human life experience in a holistic way and seeks to make explicit the meanings we attach to the lived world (Finlay, 2011). The works of Merleau Ponty and Kontos have described an embodied approach to phenomenology, whereby our physical body links us to our cognitive, emotional,

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[1] It should be noted that selfhood and personhood are two different terms. Personhood is the term used by Tom Kitwood, and selfhood is the term used by Steven Sabat. When referring to the work by either author, the relevant term will be used. Other authors use the terms according to which author they are following.

relational, and social worlds in a pre-reflective (or automatic) way. When we become unwell, the illness, disability or disease creates a focus on the part of our body which is affected, and the connection between our body and the world changes meaning we have to learn a new way of ‘being-in-the-world’ (Finlay, 2011). When this thought is applied to people with dementia, it becomes very powerful: dementia affects how a person perceives their own body, the world around them, and the actions of others. This means that we cannot make any assumptions on the experiences of a person with dementia and should seek to understand the individual’s life world.

In order to establish if the occupational engagement framework was applicable to people with dementia, it is essential to investigate their experience of occupations, i.e., the value they place on them, the consequences of participation, and the reasons for the choices they make with regard to occupations. In order to access this experience and understand the meaning of this, the person with dementia should be involved in the research directly. Hughes (2014a, p.90) states that the stories of people with dementia are “full of meaning” and that to deny a person with dementia to share those stories not only conveys a significant message about how we view those with dementia, but it undermines their “standing as a situated human being”. For this reason, it was decided that people with dementia should be directly involved in the research, and that appropriate methods would be chosen to allow this active participation.

For the purpose of this research, in keeping with my own beliefs about approaches to dementia care and in order to investigate the lived experiences of the participants, a hermeneutic phenomenological approach was adopted. This approach seeks to study and understand the narratives of individuals so that we can discover their experiences in their lifeworlds (daily lives) (Neubauer et al., 2019). Not only does this approach seek to understand these experiences, but it also allows the researcher to interpret the experiences and phenomena of the participants through the individual’s lifeworld (Neubauer et al., 2019). The hermeneutic phenomenological approach acknowledges that the researcher exists within their own lifeworld, and as such has a wealth of previous knowledge and experience which are invaluable to the research process and interpretation of the data (Neubauer et al., 2019; Emiliussen et al., 2021). Whereas a more transcendental approach might ask the researcher to ‘bracket’, or set aside, their own previous knowledge and experience, the hermeneutic approach acknowledges that we cannot completely free ourselves from our preconceptions and that we are embedded in the phenomena we are examining (Emiliussen et al., 2021). Hermeneutic phenomenology embraces this embeddedness, allowing the researcher to use experiences from their own lifeworld to reflect on another. However, in order for the research to retain academic rigour, it is essential that the researcher is open in acknowledging their own preconceptions, and in reflecting on how these may have influenced the research (Moran, 2000). Grondin (2002) describes how this can be achieved by engaging in the hermeneutic circle, whereby the researcher reads the data, constructs an initial understanding, engages in reflective writing, and then re-engages with the text with revised understandings. This process was completed several times during this research, with the data being visited several times, producing new understandings each time. With each new understanding followed a reflection on how this related to occupational engagement, and specifically in relation to the original framework by Morris (2012). Finally, a new framework was created based upon the experiences of the participants which provides a deeper understanding of the lifeworld of those who took part in the research.

It was important during the analysis of the data that a focus on the phenomena being studied was maintained. The participants shared many interesting experiences, and this gave rise to more questions and thoughts pertaining to their lived experience, but this served as a derailment from the original phenomena being studied. Bynum and Varpio (2018) stressed the importance of this, stating that researchers must avoid distractions in the analysis of data, and remain focussed on the phenomena under study. It was discovered that this is not as easy as it sounds – especially when the researcher is interested in the whole lifeworld of the participants!

4.1 Methodological Considerations

A person-centred approach to individuals helps us to develop a deeper awareness of the illness and how it affects people, influences care provision, and shapes how we involve people with dementia in research (Leadbeater, 2015), and therefore was used in the design of this research in order to understand the individuals' experiences of occupation. The person-centred approach used to design this research makes the assumption that although the person has a diagnosis of dementia, they continue to be a person with life experiences and who influences and is influenced by the world around them. In order to enable the individual to be an active participant in their world, we must support them as individuals to allow them to experience this fully. This was a central factor during the design and delivery of the research process: how best to carry out the research so that the person with dementia is supported in participating, minimising the effects of the symptoms of dementia so that they are able to understand the process and share their experiences openly.

In recent years there has been a shift in the focus of research, especially within the field of dementia. Historically, the person with dementia was not included in the research process, and the research was done 'to' them, rather than 'with' them (Wilkinson, 2002; Alzheimer Europe, 2013). This predominantly relates to the traditional ideation that a person with dementia had lost their 'self' and was no longer able to contribute to society (and equally the research process) (Davis, 2004; Singer, 2014). However, this approach marginalised the person with dementia, and the dawn of the reconceptualised person-centred models of dementia care has resulted in a shift in research methods which are now more inclusive of the person with dementia. Much of the literature in this area dates back to the late 1990's and early 2000's and reports that there is a long way to go methodologically to ensure that the ethical requirements are met when engaging people with dementia in research. However, newer literature (e.g., McKeown et al., 2010; Wiersma, 2011; Lindsay et al., 2012) demonstrates more innovative and inclusive ways of including the person with dementia in the research process, whilst ensuring concordance with the ethical requirements.

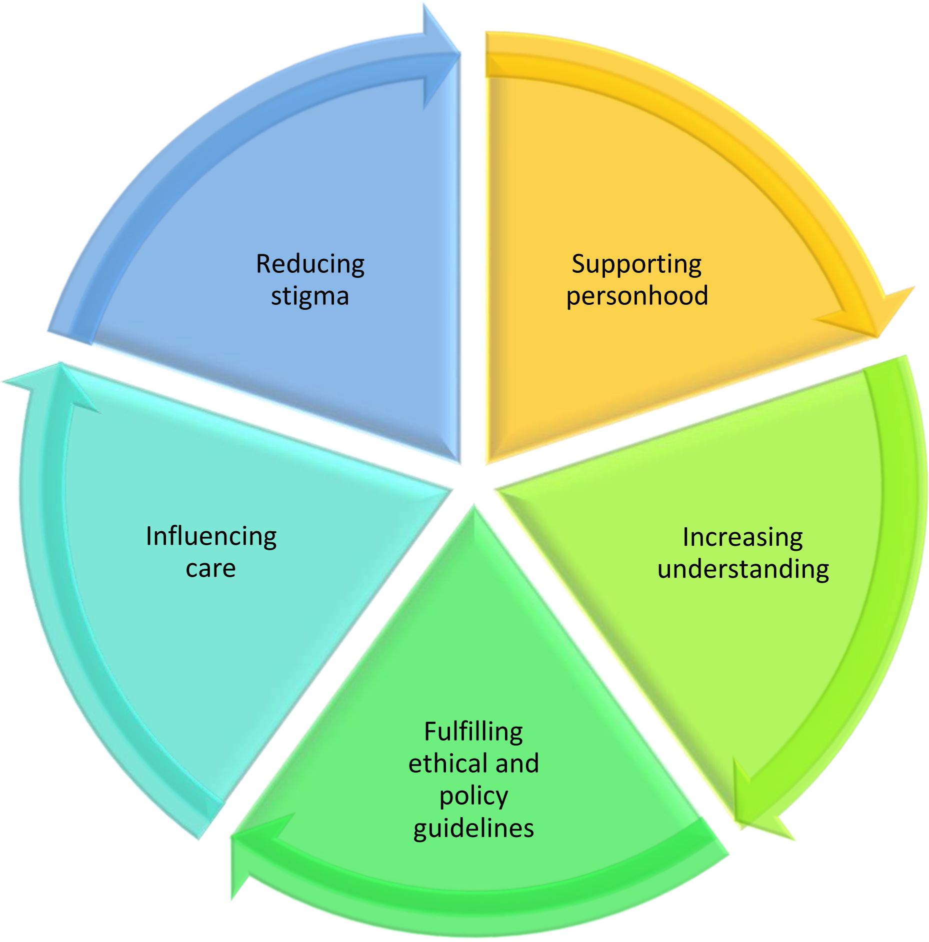
Involving people with dementia in the research process has many benefits, not least because it can help to reduce the stigma attached to the illness by demonstrating that they continue to have valid experiences and are able to express their thoughts, feelings, opinions, and views in spite of their diagnosis (Sabat, 1994; Wilkinson, 2002). Failing to include people with dementia in research reinforces the negative stereotypes held around incapacity and dementia, and therefore participatory research can challenge the stigma that people with dementia encounter from the academic world, care providers and society as a whole (Wilkinson, 2002; Moore and Hollett, 2003; Wiersma, 2011).

Research which seeks to gain insight into these experiences provides a valuable insight into the lives of people with a diagnosis of dementia, which deepens the knowledge of the illness and enables the development of care practices in the area of dementia care (Cohen-Mansfield et al, 2000; Nygård, 2006; McKeown et al, 2010; Wiersma, 2011). It provides valuable information on the perspectives and experiences of the people affected by dementia, broadening understanding of the illness from the more historical research which centred on the clinical effects of dementia and the impact of caring for a person with dementia on caregivers (Moore and Hollett, 2003; Cotrell and Schulz, 1993; Wiersma, 2011).

The inclusion of people with dementia is very much supported by government policy and guidelines. This was first indicated in a project paper produced by the Kings Fund Centre in 1986, which campaigned for a move towards a more person centred and rights-based approach to dementia care and research into dementia. More recently, the Mental Capacity Act (2005), the Dementia Strategy (2009) and the Prime Minister’s Challenge on Dementia (2012 and 2015) have sought to improve the rights of people with dementia and to ensure that care of people with dementia and research conducted around dementia is inclusive and actively seeks the views and opinions of the person with dementia.

Figure 5 below summarises the key benefits of including people with dementia in the research process. Together, these points serve to ensure good research in the field of dementia care. However, there are many factors which need to be considered in order to protect the person with dementia and ensure that research is safe and ethical. These are complex and are discussed in detail in the following section.

Figure 5: The benefits of including people with dementia in research (created by Hampson, 2021)



Various approaches have been described which can be used to include the person with dementia in research. These have all involve the person with dementia in varying degrees and are described below:

Emancipatory research (Wilkinson, 2002): this is where the person with dementia is involved in the research process, for example in designing the research project. The person with dementia may also be involved in collecting and analysing data, and in writing up the research.

Participatory research (Wilkinson, 2002): in this approach, the person with dementia is given opportunities to describe their own opinions and experience, and is encouraged to analyse their situation to ensure that the outcome of the research reflects an accurate description of their experience.

Collaborative research (Knox et al., 2000): this approach views the research participant as an expert and a research partner/colleague. The participants are given a pivotal role in controlling the research and their involvement within it, working collaboratively with the inquirer to guide the research and to ensure the correct meaning is extracted from the information provided. This approach seeks to empower the participant, and is thought to be a positive approach to including marginalised groups of people (in this case, people with dementia) in research (Knox et al., 2000).

These approaches to dementia research are a very positive move forwards in obtaining the views of people with dementia directly in order to create a greater understanding of the effects of dementia in order to influence models of care. However, careful consideration should be given as to the method used in order to ensure the involvement of the person with dementia is appropriate, accessible, and ethical.

For the purpose of this research, the modes of involvement centred around participatory and collaborative research methods. The reason for this was predominantly because the topic for research was agreed in advance. Emancipatory research would have involved people with dementia in deciding the topic area as well as involving them in the research design process. It was felt that participatory and collaborative approaches would work well in eliciting reliable and meaningful data around occupational engagement, while ensuring that the person with dementia agreed that the data was representative of their experience. The very nature of this approach lends itself well to qualitative approaches, where the data collected is more descriptive.

4.2 Methodological Considerations when Including People with Dementia in Research

Earlier literature describes areas to consider when engaging people with dementia in qualitative research (e.g., Froggatt, 1988; Clarke and Keady, 2002). This information, while appropriate at the time of writing, is now outdated as the research process has moved on in recent years, with researchers using more innovative and creative ways to engage people with dementia in research. For example, Froggatt (1988) suggests that access to people with dementia is only gained through health practitioners or social services. However, this is inaccurate today as access can also be gained through third sector agencies (e.g., the Alzheimer's Society, Age UK), and through agencies such as Join Dementia Research, where people with dementia can volunteer for research independent of primary or secondary health care services. This is important for dementia research as it allows for wider access to people with dementia by researchers. Froggatt (1988) also suggested that caregivers should be a key part of research with a person with dementia, however more recent research has strengthened the consent process which means that reliance on caregiver information is less (e.g., Dewing, 2002; McKeown et al, 2010; Bartlett, 2012). Additionally, McKillop[2] and Wilkinson (2004) state that whilst caregiver input can be helpful in reminding the person about interview appointments and/or completion of diaries or other research tasks, heavy reliance on the caregiver for consent and information-giving should be avoided. The person with dementia has the right to free choice, should be treated as an individual with valuable experiences of their own, without asking the caregiver to corroborate everything and make choices on their behalf.

Froggatt (1988) also states that funding for research into dementia may be difficult to obtain. Thankfully, this changed following the G8 Summit (2013), in which first world countries pledged to promote and fund research into dementia

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[2] McKillop is a researcher who has a diagnosis of dementia and who strives to improve the inclusion and participation of people with dementia in research. His work promotes methods to ensure the inclusion of research with people with dementia about topics which affect them.

in order to improve care and treatments for those with a diagnosis. At the time of writing, there were many specific sources of funding for research into dementia, for example the Dementia Alliance, The Alzheimer's Society, as well as more locally sourced funding for dementia research. This is a positive move forwards in increasing opportunities for dementia research, allowing the voice of people with dementia to be heard.

Gibson et al. (2004) describe the participatory nature of qualitative research into dementia. They state that qualitative research provides detailed data and provides an opportunity for learning for both the participants and the researcher, as knowledge is exchanged. However, because of the nature of disability caused by dementia (i.e., expressive language problems, memory deficits, anxiety in new situations), research into dementia can be difficult. In order to overcome this, some researchers have adopted more creative and artistic ways of carrying out research which provides opportunities for accessing the opinions and experiences of people with dementia beyond the more traditional methods of interviews and observation (Bartlett, 2012; Wiersma, 2011). It has also been suggested that a mixed methods approach can provide a greater depth of knowledge, particularly in dementia research. This type of method has a range of strengths, for example having a broader focus, the ability to gather a greater depth and complexity of information, compensating for any shortcomings of the individual methods used, and highlighting any assumptions of the researcher (Giddings and Grant, 2006). Although this research is not a 'mixed methods' study (i.e., does not combine quantitative and qualitative methods), it does make use of more than one qualitative method to help obtain a greater depth of data and understanding.

4.3 Methods Chosen

This section describes the methods chosen for this research. All were chosen carefully to allow the maximum participation of the individuals and to support them in sharing their experiences as openly and accurately as possible. Whilst this is good practice when involving people with dementia in research, it is also strongly linked with the phenomenological approach taken in this research, encouraging individuals to share their opinions and views so that we can understand their lived experience of the world. This also adds to the authenticity of the research as the views and opinions of the individuals were recorded, rather than the views of others, such as caregivers. It should also be noted here that prior to the commencement of the research, ethical approval was sought and gained via the University of Cumbria (please see Appendix 4).

4.3.i Observation

The use of observation within research is considered as complementary to interviews in the quest of giving the person with dementia a voice in which to express their experiences (Hubbard et al., 2003). Both observations and interviews are "constructive collaborations" between the researcher and the participants (Hubbard et al., 2003, p.360), and are described as meaning-making occasions (Gubrium, 1993; 1995). For the purposes of this research, the observations were used as a tool to develop a deeper understanding of the participants' experiences during the activity, and this allowed for in-depth discussion about what these experiences meant to the participant during the interviews. The observations also allowed testing of the language used within the Occupational Engagement Framework, to discover if they are workable in an observatory capacity for the therapist.

During the observations, photographs were taken of the activity or of the items made to prompt and remind participants of the activities they have participated in. This is potentially very useful when carrying out research with people with dementia, and indeed the use of photographs has been used within a number of studies with people with dementia (Genoe and Dupuis, 2013).

In support of this, Harper (2002) stated that the use of photographs can be useful in enhancing interviews because parts of the brain which process visual information are evolutionarily older than those which process verbal information, and therefore more detailed information can be gained. This was further supported by Genoe and Dupuis (2013), who stated that the brain responds differently to verbal and visual information.

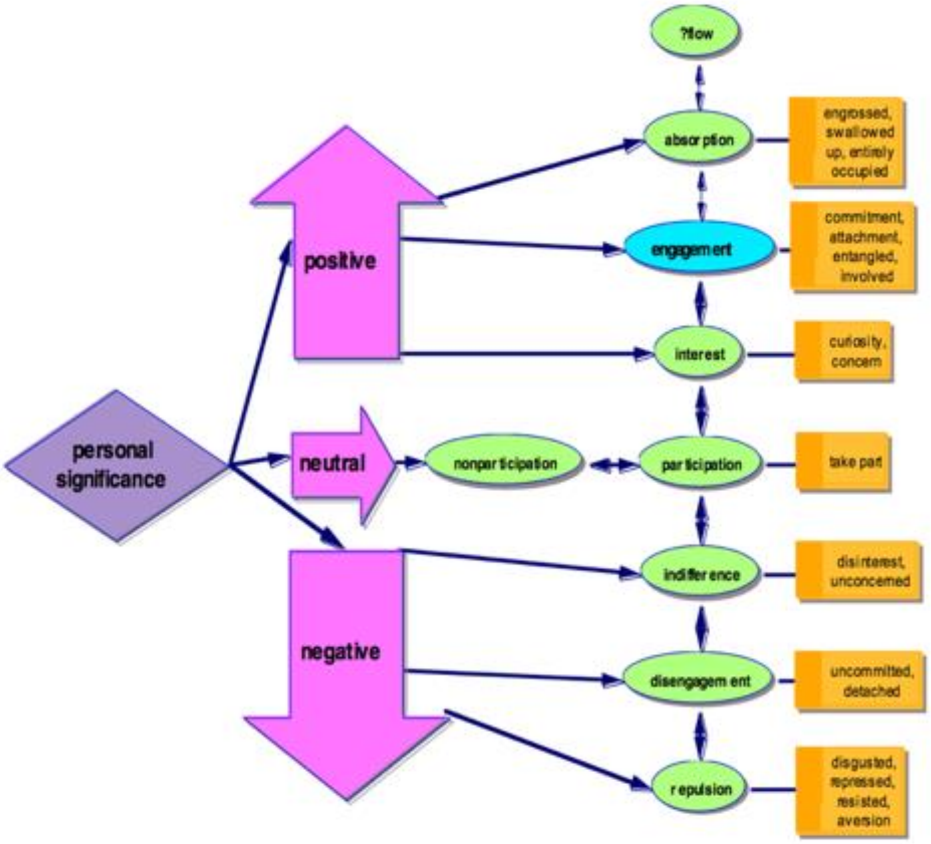
It was initially intended that a photograph would be taken of the participant carrying out the activity, however this did not feel comfortable or appropriate during the activities for the participants or the researcher. From the researcher perspective this was because it was felt that it would be too disruptive to the rest of the group and may have distracted the participant from what they were doing, thus affecting their participation. From a participant perspective, several people stated that they felt uncomfortable having their photographs taken. Therefore, photographs of the activity were taken towards the end of the group, or afterwards, depending on the activity and tended to be a picture of the outcome of the activity. The photographs were then used to remind the person of the activity during the interviews, where required. Permission to take the pictures was gained each time, even though the person was often not in the image. This is because the thing being photographed was often a piece of the participant’s work.

This was much easier when the product of the session was created by the group as a whole, however some participants were uncomfortable with photographs being taken of their own personal work. In most cases, a reminder of what the pictures were to be used for (i.e., reminders of the activity for the interview) was enough to be given permission to take the pictures. One participant stated that I could not take a picture of her work and insisted that I photograph my own work instead. As this was very similar to her own work, it was felt that this would be an acceptable reminder during the interview.

Interviews about the activity and images produced were conducted shortly after the activity took place. Initially, it was hoped that this would be on the same day of the interview, however this did not always happen: on occasions there were absences from the participants and/or the researcher, which meant that there were sometimes several weeks between the observed activity and the interviews. This made the use of the photographs more important. Because of the nature of the day centre, participants were observed in several activities each week, which meant that there was often more than one activity to discuss. Mostly, participants were able to recall the activity that was to be discussed, however on one occasion the participant had difficulty recalling the activity, even when she was shown the photograph.

During the observations, each participant was seen to carry out a variety of activities during their day at the centre. During the activities, an observation sheet was completed (see Appendices 5 and 6 for the form used and completed forms). The observation form was a deductive approach, which provided a priori template to the observations using the conceptual framework for occupational engagement (version 4) created by Morris (Crabtree and Miller, 1999; Fereday and Muir-Cochrane, 2006; Morris, 2012). This version of the framework (see Figure 6) suggests features of each value which may be present and observable in a person carrying out an occupation, which are not visibly present in later versions of the framework. These factors provided a code for the observations and therefore provided a useful tool for documenting each person’s participation in the activities observed and a basis to begin testing the framework. It is acknowledged that these are not exclusive, and that the observations are subjective, however it was the intention that this can then be checked with the participants in the interview phase.

Figure 6: Conceptual Framework for Occupational Engagement, Version 4 (Morris, 2009, cited in Morris, 2012)



4.3.ii Interviews

In addition to the observation and photographs, it was considered that semi-structured, in-depth interviews would be a useful way of gaining a deeper understanding of the experience of occupation when a person has dementia and would allow exploration of the values associated with occupation and the consequences resulting from participation. Interviews have been used in many studies to explore the perspective of the person with dementia. In this research, it was hoped that this approach would lead to a greater understanding of what makes a person participate in occupations, what value the participation holds, and what an imbalance of occupation means for a person with dementia in terms of their sense of ill-being and wellbeing. The nature and symptoms of dementia mean that the interview technique requires special consideration (Pratt, 2002).

Smith et al. (2009), state that a researcher should have the following qualities:

- Open mindedness
- Flexibility
- Patience
- Empathy
- Willingness to enter into and respond to the participant's world

These qualities are especially important when carrying out research with a person with dementia: because of the nature of the symptoms of the illness, the researcher will need to be flexible, patient and demonstrate empathy, and will also need awareness and understanding that the lived experience of a person with dementia can be very different to the reality of others (e.g. they may believe it is a date 20 years previously, they may believe that the venue is their home/a hotel, they may believe the researcher is a family member). By entering into the participant's world, we are able to step into their shoes and walk around in them to understand their lived experiences (Pietkiewicz and Smith, 2014). It is important in dementia care and also in research that this lived experience is respected and analysed accordingly in order to give a voice to people with dementia and to support the self of those involved.

It is important that the researcher consider the questions asked of people with dementia. Often, people with dementia have difficulty with recalling facts and therefore questions which relate to feelings and experiences may be more successful in eliciting useful data and minimising distress (Pratt, 2002).

The comfort of the individual is extremely important for the interview to be successful. McKillop and Wilkinson (2004) suggest the following advice for making the person with dementia feel more comfortable and open during interviews:

- Find a comfortable place for the interview: consider temperature, reduce noise and other distractions, avoid places where others can look in/watch, avoid sitting with the sun behind you so they can see you clearly.
- Do not sit behind an obstacle e.g., a desk.
- Be yourself at all times.
- Make eye contact and talk directly to the person.
- Accept a cup of tea/coffee/water if you are offered as this nurtures a sense of hospitality and helps people to feel comfortable.
- Consider the time of day: afternoons can be a tiring time of day for people with dementia. Check with the person when they are most alert and open to questioning.

The researcher-participant relationship is also of importance, and there are certain techniques that researchers can use to make a person with dementia feel more at ease. Icebreakers (e.g. biscuits, a bunch of flowers, sweets, refreshments) can help; if you are in the person’s own environment, admire something they are passionate about (e.g. photographs of family, pets, garden); smile and pay attention to what is said – you may be required to help the person if they become lost in conversation; show empathy but not pity; show a caring personality; do not take extensive notes on a large pad – use a small notepad and make notes sparingly; don't point out contradictions; if interviewing a person more than once, demonstrate interest by remembering something from the previous interview; if the researcher and participant begin to speak at the same time, allow the person with dementia to speak first so that they do not forget what they were going to say (McKillop and Wilkinson, 2004).

In the same way that building relationships is important, so is exiting the interview. At the end of an interview, leave the person with a feeling of achievement, and provide any information of the progress of the study (McKillop and Wilkinson, 2004).

These principles were followed during the interview process. A quiet room away from the hustle and bustle of the day centre was found. Participants were made a drink of their choice to enjoy during the interviews, and careful consideration was made about the ambiance of the room: windows were opened or closed accordingly for temperature, blinds closed when the sun was bright, and the furniture arranged so that there was no desks or tables between the researcher and participant. The principles described by McKillop and Wilkinson (2004) were followed so that the participants were able to feel as relaxed as possible and to allow them the opportunity to speak openly and comfortably about their experiences of occupation. Time was taken to speak to the person about their day so far and where necessary, gentle reminders were given about what we were speaking about. The principles were very useful in facilitating the participants to speak openly and honestly about their experience of dementia and occupations, leading to some very personal, emotional conversations.

4.3.iii Interviewing Highs and Lows

The interviews were conducted at the centre in a quiet room away from the main activity of the centre. The interviews were semi structured and had a loose schedule/guideline to follow. Care was taken to allow the participants to speak, allow silences for reflection and to allow the participant to finish what they were saying (Smith et al., 1997; Smith et al., 2009; Pietkiewicz and Smith, 2014). During the interviews, it was essential that I remained cognizant of my own 'thrownness'. This is a concept in hermeneutic phenomenology which describes how, as humans, we have experiences and preconceptions that are embedded within a phenomenon (Emiliussen et al., 2021). When carrying out the interviews, it was important that I remain aware of my own thrownness, and try to ensure that the experiences of the participants were as explicit as possible in order to reduce the influence of my own experiences and preconceptions. This was particularly important when the participants were talking about experiences that we shared or which I had previous experience of (either in my own lifeworld, or in the lifeworld of people with dementia that I have previously encountered). This was achieved by careful listening, and by checking with participants what they meant. This gave a deeper understanding and also ensured that the interpretation which would later arise from the interviews was as close to their own experiences as possible. The checks were made to ensure that my understanding was correct in order to check my own understanding of what was being shared. This was a very interesting and necessary part of the interviews, because on occasion my understanding of what the person was trying to say was very wrong. This clarification brought some interesting insights and was an essential step in understanding the lived experience of each participant.

Following the initial interviews, the participants were again observed and interviewed about the activities they had participated in. This time, the questioning went a little deeper to try and focus on their experiences. In order to do this, I had to ask the participants to describe in detail what their experiences were, making no assumptions about what they meant (Smith et al., 2009). This allowed me to 'walk in the shoes' of each participant to gain an understanding of their experience of each observed activity within the centre (Pietkiewicz and Smith, 2014).

The interviews were often lengthy, and several participants became tired during the sessions. Several terminated the interview, and two participants were visibly tiring as the time progressed. This was evident in the tone, speed, and content of their speech. At this time, the participants were able to guide the conversation more so that they were not placed under undue stress. It was evident also that some participants were unable to answer the questions in great depth. One participant stated that she was unable to answer the questions, whilst others had difficulty finding the words they wanted to say to describe how they felt. At these points, the conversation was moved on. At times, and where appropriate, suggestions were made to clarify what was being said and to assist the participant in finding the right words. This was difficult at times as it could be seen as leading the participant, so great care was taken to try and avoid this.

4.4 Accessible Information Sheets and Consent Form

In order to gain initial, formal consent from participants an information sheet and consent form were provided to all potential participants (see Appendix 7). The information sheet and consent form are based on the informed assent form for children/minors example provided by the World Health Organisation (2017a). Although existing guidelines exist for assessing capacity and seeking consent, it was felt that a more robust process was required with the participants of this research. This was in part because ethical approval was granted for those who are able to provide consent, and also because it was at times unclear if those approached to participate had capacity. It was felt to be important that those approached to participate were able to fully understand the research and what it entailed, and also that the information was presented in a clear format with opportunities to ensure understanding and allow specific questions to be asked. The format of the form used provided a simplistic breakdown of the research and provided options for recording any questions for discussion at a later time. It was also felt that using this format would help to establish the capacity and understanding of the potential participant, in so much as if they cannot understand and retain the individual smaller sections, they may not have capacity to consent and either should be omitted from the research or further capacity assessment conducted as per the Mental Capacity Act 2005.

A separate information sheet has been created for gatekeepers (see Appendix 8). This provides similar information to the one provided for participants, but is not as simplistic in terms of language, and covers other concerns that gatekeepers and third parties might have.

All leaflets and forms were checked for reading age (using the Microsoft Word feature) and were rated as being easy to read. The font used was ‘arial’ in a font size of 12, as recommended by the Dementia Engagement and Empowerment Project (2013). It is hoped that this will increase the opportunity for people with dementia to engage in the research by making information as accessible as possible.

4.5 Methods Pilot

Prior to commencing the research with people with dementia, a methods pilot was conducted. This involved a person who does not have any issues around capacity and consent, and who was willing to participate. A visit took place to this person’s house, and they were observed carrying out an activity (making a cup of tea). Photographs were taken and an interview conducted to check the interview schedule. The interview was transcribed to practise this technique. Following the methods pilot, some minor changes were made to the interview schedule, however it was felt evaluating the method with a person with dementia would provide a more realistic impression of how this would work within this research with participants. The information gained from the initial pilot is not included in the data of this research.

A second pilot was conducted within the day centre with a person with dementia, who was a participant of the research. The interview schedule developed following the initial pilot was used, however it quickly became apparent that this was not an appropriate format for the interviews to follow. It was clear that although some questions were useful to help guide the interview and keep it on track with regard to the topic of occupation, participants also had their story to tell, which did not always follow a pre-designed schedule. As such, the remainder of the interviews were conducted with a minimal schedule which allowed the participants to share their own personal story and control the direction of the interviews. This was a very useful approach, and as such conversations within the interviews were much more person-centred and much more data obtained.

4.6 Identifying Suitable Participants

In the first instance, access to people with dementia who would be appropriate for the study had to be arranged. For the purposes of this research, it was decided that the NHS would be an inappropriate place for the recruitment of participants. This view was based on my current experience of dementia care within the NHS: people with dementia are involved in NHS services for the purposes of diagnosis or when they are in crisis. I felt that it would be inappropriate to approach people who had just received a diagnosis, as this is often a distressing time and a period of significant acceptance and adjustment (Pratt and Wilkinson, 2001; Pratt and Wilkinson, 2003; Vernooij-Dassen et al., 2006). Similarly, those in crisis would be inappropriate for the research because of their current mental state, and also because they may lack the capacity to provide informed consent to participate in the research. I also considered approaching national charities, such as Age UK and the Alzheimer's Society, and applying to Join Dementia Research to access people with dementia. However, considering the time constraints of the research I decided to approach a smaller charitable agency within the geographical region I am based. The agency provides specialist day services for people with dementia and is independent of national charities. I approached the charity and held meetings with the managing staff to explain the purpose of the study and what it will involve for both the centre and the people with dementia. The ethics requirements of the charity were also checked to ensure that the University approval was sufficient. A further consideration was that the service was outside of the catchment area in which my NHS work is conducted, in order to minimise the 'insider-outsider' issues which could influence the research should

I encounter a person whose care I had previously been involved in. There is further discussion about the insider-outsider issues in Chapter 17.

Once the centre had been granted permission for the research to be conducted within their premises, I began to spend some time there with the staff and those who attended. This was to help eliminate any suspicions from staff about the research process, and also to get to know the attendees. The benefits of this were three-fold: I was able to identify those who would be appropriate for the study through observing them in activities and speaking to them; I was able to make myself more familiar to the potential participants so that they felt more comfortable in my company; and I was able to establish how the people I would later recruit communicate and determine any factors which might signify assent or, more importantly, dissent.

4.7 Sampling

Selection of the participants in this research was purposive i.e., they were chosen specifically because they could offer an insight into the experience of occupation from the perspective of a person with dementia (Smith et al., 2009). The sample was homogenous (i.e. the participants have qualities in common) so that the Occupational Engagement Framework can be applied to this group of people (Smith et al., 2009). For this study the commonalities were that all participants had a diagnosis of dementia (type of dementia was not considered relevant), all participants attended the day centre and participated in activities, all participants had capacity to consent, and all participants were able to communicate verbally. While it is accepted that people with dementia who have communication difficulties are able to participate in research, it was felt that the inclusion of people with communication difficulties would potentially cause distress to them and may result in a false understanding of meaning. It is acknowledged that the selection of participants in this way affects the generalizability of the study, in so much as it limits the findings to one particular group of people. However, as suggested by Smith et al. (2009), theoretical transferability is possible where links can be made with existing literature and personal experiences. This is also possible because the original work conducted by Morris (2012) followed a grounded theory approach, which in itself “generates conceptual hypotheses that get applied to any relevant time, place, and people with emergent fit” (Glaser, 2002, p.25).

The selection of individual participants developed through the observations and interactions made during the time spent at the centre. The people identified were discussed with the manager of the centre to ensure that my observations were correct and they would be appropriate for the study. In total, six participants were recruited for the study. This is a small number, but allows for in-depth observation and interviews to be completed.

4.8 Gaining Informed Consent

Each participant was approached individually to establish if they would be happy to participate in the study. All those approached stated that they were happy to participate. Once initial consent to proceed was established, each person was provided with a copy of the invitation letter and participant information sheet (see Appendix 7 and 9). Where relevant, a third-party information sheet was sent home for their relatives and/or caregivers (see Appendix 8). The information sheets were carefully designed using the considerations previously discussed. A template from the World Health Organisation (Informed Assent for Children/Minors) was adapted. This was used because the language was simplistic, and the format was clear. The design also allowed for checking the participant’s understanding of the research procedure, which I felt was useful in establishing capacity to consent. A summary was added at the end of the document because it is long. In addition, I added a photograph of myself and a short introduction to help the participants to recognise me and feel a little more familiar with me. This raised several comments whilst the document was being checked, but also proved useful for participants as they were able to identify me as the researcher subsequently.

The document was checked for readability, in order to ensure that the language was accessible. Checking the readability is essential because written information is fixed, as opposed to spoken information, which can be adjusted according to the requirements of the listener (Williamson and Martin, 2010). It is recommended that patient and public information leaflets are checked to ensure that the reader understands any unfamiliar terms and concepts presented in the document (Wilson, 2009; Badarudeen and Sabharwal, 2010; National Institutes of Health, 2013). It is suggested that the average reading age within the UK and the USA is age 13-14, however for patient information leaflets, it is recommended that reading age is age 11-12 (grade 6) (Wilson, 2009; Williamson and Martin, 2010). The readability function on Microsoft Word was used to check the participant and third-party information sheets and showed the following statistics: Flesch reading ease: 84.6, Flesch-Kincaid grade level 4.9. A Flesch score higher than 60 and Flesch-Kincaid grade lower than grade 6 is considered to be good (Williamson and Martin, 2010).

At the end of the document is the consent form, which was signed by each participant once we had read through the information together. A copy of the consent form was provided to each participant for their records.

4.9 Consent Conundrums

During the process of establishing consent, there were two issues which arose which challenged the ethical standards of the research. These were unexpected and required intervention to ensure the safety of the participants.

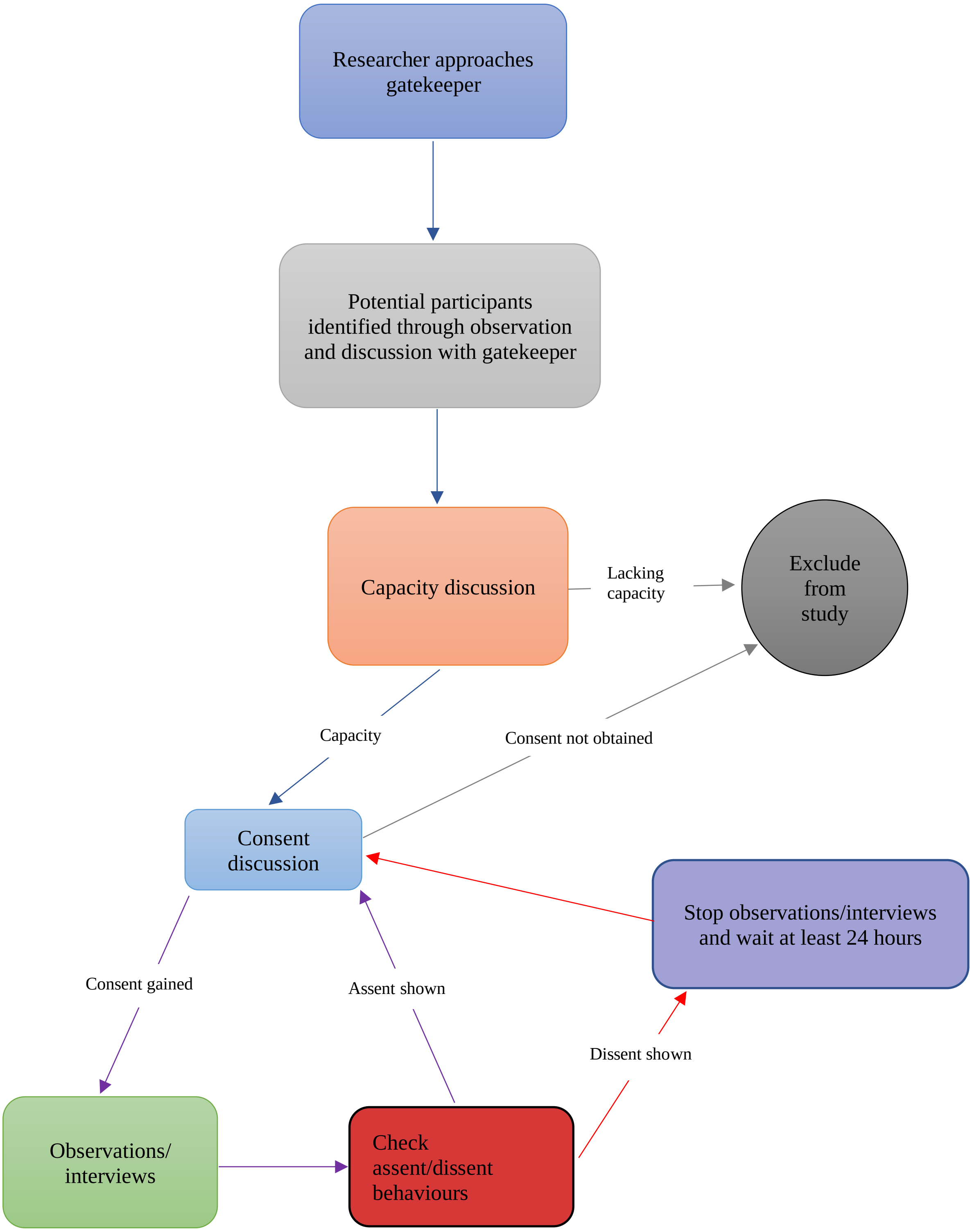
During the consent meeting for the first participant, Fran, became distressed and tearful whilst talking about her home situation. Whilst this was not a topic instigated by the researcher, she clearly felt that this was an opportunity to discuss the issues she was having in a safe place. During this discussion, she disclosed that she has been having suicidal thoughts. The initial response to this was to check with her that she did not have any plans to harm herself and was not at any immediate risk. She was informed that I would need to inform the day centre manager so that we can keep her safe. Reassurances were given, and she was allowed the opportunity to speak about this further. As soon as the meeting was over, the day centre manager was informed, and she stated that she would inform the relevant authorities for support. I did not feel that I required a de-brief or supervision following this, however I did inform my supervisory team so that they were aware of the event, and a reflection was written.

Whilst obtaining consent for Peter, I became concerned that the gentleman in question did not have capacity to consent. During the consent meeting he did not ask any questions, and he did not appear to understand the context of the research. However, at the end of the meeting, he was asked what he understood of the project, and he gave a comment which demonstrated that he understood what was going to happen and why. This was later checked with the day centre manager, who confirmed that the gentleman in question did have the capacity to participate.

4.10 Ongoing Consent, Assent, and Dissent

Throughout every encounter with the participants, their consent was checked using the framework in Figure 7. This is a combination of the models produced by Black et al. (2010) and Batchelor-Aselage et al. (2014). This framework is cyclical in nature: capacity is established, consent is obtained, and the interviews and observations were conducted with assent and dissent at the forefront of the interaction. This was completed for observations, photographs and for interviews. Careful checks were made to ensure assent was present and to ensure that no signs of dissent were being demonstrated. While no signs of dissent were demonstrated, one participant did demonstrate signs of being tired during the interview. She later terminated the interview by stating that she was going to the toilet.

Figure 7: Consent Process Framework (Hampson, 2021)



Further reading was completed and published around the challenges of consent in research with people with dementia, and this is presented in Appendix 3 (Hampson and Morris, 2018).

4.11 Confidentiality

Cox et al. (2014, p.9) define confidentiality as:

> "*...a commitment to protecting an individual's privacy when that individual has disclosed information in the context of a relationship of trust.*"

This means that the researcher has an ethical requirement to protect the participants by ensuring that any information (verbal, visual or otherwise) disclosed during the study remains unidentifiable to the participant. By their very nature, qualitative studies collect vast amounts of very personal, detailed information which can make them identifiable, and as such anonymity and confidentiality is a huge concern for researchers (Richards and Schwartz, 2002).

In this research, the individuals who participated in the study will remain anonymous, i.e., their names have been changed and all identifying data removed from publication. Pseudonyms were used when transcribing the interviews and labelling photographs, and all data (photographs, audio recordings and transcripts) stored on secure password protected and encrypted devices (Richards and Schwartz, 2002). Initially, the photographs and audio recordings were taken and stored on a mobile device which is encrypted and password protected, and later transferred to a computer which is also secure.

The use of visual media (photographs) however complicates the more traditional views of confidentiality and, in some cases, consent (Clark et al., 2010; Gubrium et al., 2014). As described by Cox et al. (2014), digital photography is capable of capturing "detailed and intimate" portraits of individuals, and the information in these images can be used to identify the participants, researchers and/or third parties. The identifiable features of a digital image are harder to eliminate, and also include factors such as GPS, automated facial recognition and place recognition, all of which could be used to identify an individual (Switzer et al., 2015).

In this study, the images were taken by the researcher, and were captured on a mobile device. In order to ensure confidentiality, the device was password protected and encrypted. The GPS detection was switched off to prevent a location stamp being placed on the image. The image remained on the mobile device until after the interview (the image will be required during the interview), after which it was saved onto the University of Cumbria OneDrive (an online storage facility which is password protected, encrypted, and protected by the institutional security, and deleted from the device and any cloud (online) storage associated with this.

Consent must be gained from participants for the photographs to be taken and to be reproduced, with clear instruction given about the use of these photographs. It was intended that the photographs would be reproduced in the writing up of the study (i.e., the thesis), and possibly in dissemination of the research e.g., in presentations. Consent is essential if there are to be pictures of the faces of participants, and it was anticipated that the photographs may contain facial shots in order to capture the elements of engagement. It is suggested by Switzer et al. (2015) that if consent to reproduce the photographs is not obtained, that the photograph is either not included or that the features of the person are blurred. However, they go on to state that blurring or blacking out of the image may imply illegal or immoral behaviour and may remove or reduce important detail about what is being researched (i.e., occupational engagement), and therefore weaken the methodological argument for the use of photography.

Others may be captured in the photographs who are not part of the study or who have not consented to being involved, e.g., other day centre attendees, gatekeepers, members of the public (Clark et al., 2010; Gubrium et al., 2013).

This provides issues around confidentiality which will be dealt with by blacking out any identifiable features of individuals who are not participants of the study.

Another area to consider is that of institutional confidentiality and consent. The day centre used within the research may not be happy to have the venue photographed (Radley and Taylor, 2003; Switzer et al., 2015). It is therefore important to liaise with gatekeepers (i.e., day centre managers and staff) to gain pre-approval to take photographs within the centre. This will clarify where the photographs can be taken and what information they can contain. This must be a consideration in the study information provided to the gatekeepers, so that they can have discussions around where photographs are taken and whether there is anything they do not give permission to be photographed. It is also essential here that any information which makes the venue identifiable e.g., day centre names, street signs, are not captured in any photographs, and if they are that they are removed, covered, blurred or blacked out. This will help to ensure the confidentiality of the participants of the research. During discussions with the day centre manager, it was established that there were no concerns about the protection of the centre. In fact, the manager asked if the centre would be acknowledged, as this will help raise their profile and potentially help with the tender process. It was explained to the manager that I would be unable to identify the centre because of the requirement to maintain the confidentiality of the participants.

In the practicality of capturing the images, no facial images were captured of the participants which helped to ensure their identity is protected. Hands were occasionally captured, but mostly the product of the activity was captured. While this perhaps detracts from capturing the entire essence of the experience of the activity, participants generally stated that they felt happier about this.

For the interview recordings, a mobile phone was used to capture the discussions held. Consent to record the interviews was obtained at each interview, and the mobile phone was placed in the centre of a table in front of the participant and interviewer. The phone was password protected, and all recordings were uploaded onto the university system and deleted from the device at the earliest opportunity. Each recording was saved with only the participant number. The recordings were transcribed by the researcher only, giving optimum opportunity for immersion in the data and nuances of the conversation. This also ensured maximum confidentiality as participants often identified others within their interviews, including naming others who were not involved in the research. These names were omitted or changed in the transcription process.

4.12 Framework Analysis

Following the data collection, framework analysis was carried out in order to analyse the information gathered from the observations and the interviews, to allow investigation of the application of the Occupational Engagement Framework proposed by Morris (2012) to people with dementia who attend a day centre. Framework analysis is a qualitative approach to research. It is well suited to research which has limitations around time and participant samples, and which has specific questions to answer and a priori issues to address (Srivastava and Thomson, 2009). The objective of framework analysis is to identify, describe and interpret the key themes and patterns which arise from the data (Goldsmith, 2021). This approach to the research also allowed the exploration of themes and patterns that arose from the experiences of the participants, thus allowing these experiences to be the main focus of the research. It also follows the hermeneutic circle of absorption in the data, identifying the key themes (and therefore constructing a vague understanding of the data) and re-engaging with the data again to produce a deeper understanding of the experiences of the participants (Neubauer et al., 2019). In turn, this allows the experiences of the participants to be applied to the original framework and for the development of a new framework which is applicable to the participants of this research.

In the case of this research, the specific question was around the application of the Occupational Engagement Framework to people with dementia in a day care setting. This limits the research participants to individuals who have a diagnosis of dementia and who attend a day centre, and also limits the analysis originally to the application of the framework to those individuals. This positions framework analysis as an ideal method to apply the original framework proposed by Morris (2012) and to then identify any new themes emerging from the data.

The process of framework analysis consists of five steps (Ritchie and Spencer, 1994):

1. familiarisation
2. identifying a thematic framework
3. indexing
4. charting
5. mapping and interpretation

Each of these steps is now discussed in greater detail.

4.12.i Familiarisation

At this stage, the researcher is required to become familiar with the data collected, in this case, transcripts, observation forms and notes taken (Ritchie and Spencer, 1994). This required the recordings of interviews to be listened to and the transcripts to be read several times in order to become immersed in the data (Srivastava and Thomson, 2009). This provided an initial awareness of the key themes arising and allowed notes to be taken of recurrent themes between participants.

4.12.ii Identifying a Thematic Framework

After the initial familiarisation, emerging themes or issues are identified from the data. It is important that the data informs the themes and issues, and these key concepts, themes and issues form the basis of a thematic framework which can them be used as a filter to further classify and hone the data collected (Ritchie and Spencer, 1994; Srivastava and Thomson, 2009). It was noted by Ritchie and Spencer (1994) that it is important to remain open minded when creating the framework, even when there are a priori factors influencing the research, so that the data is not forced into the a priori issues, allowing new themes and ideas to arise from the research.

The first stage of familiarisation occurred with the reading of the research findings by Morris (2012) and developing an understanding of the original Occupational Engagement Framework. This enabled the development of the observation forms, which identified the characteristics of each of the occupational values which might be observed or discussed. These were used to help identify the value of the occupation, which was then checked during the interviews to ensure that the observational data was accurate. Although the data was measured against the Occupational Engagement Framework, new themes arose for the individuals which were important for consideration.

Following this, familiarisation occurred when getting to know the participants. This was felt to be an important element of the research because this fostered good relationships between the researcher and the participants, and also allowed further insight into the lifeworld of each participant. Conversations which occurred outside of the interviews were insightful in that participants often shared personal information, knowing it was not being formally recorded. It would be unethical to include this in the research, but the conversations did help in the interpretation of the data as the participants had shared more about their lifeworld and current situation, adding to the depth of analysis.

The next stage of familiarisation was around the data. The audio recordings of the interviews were listened to repeatedly and transcribed, and then were read carefully to identify initial themes and commonalities. This was then repeated (listening/reading the transcripts and then checking the themes) until a final list of key themes and issues was identified. One of the difficulties that arose during this part of analysis was the identification of themes which were interesting and important to the participants, but which were not directly linked with the a priori issues. Initially, these were included in the framework, but were later put aside as this was providing too great an analysis and was leading to other issues which were not linked with occupational engagement. This task was difficult at times, especially considering the phenomenological approach, because the issues discussed by participants were important to them personally but were not applicable to the main aims of this research. It was difficult to leave those issues to one side, however incorporating them would have taken the research along a different route away from the investigation it was concerned with.

The process of refining the thematic framework is intuitive and logical, and involves making judgements about meaning, relevance and connections between ideas (Srivastava and Thomson, 2009). The process of using observations and interviews was helpful in this however, as meaning was checked with participants in the discussions around occupations to ensure that the meaning was more explicit.

The framework was developed by the researcher, and was checked by the supervisors of the research. The participants of the study were not involved in the development or validation of the framework. Whilst this would have been a purposeful task in terms of increasing the validity and authenticity of the research, it was not possible with the participants of this research. The framework analysis occurred some time after the interviews had taken place, and the majority of the participants would be unable to recall the interviews taking place. In addition, the global pandemic had begun with a nation-wide lockdown, and this made it impossible to access the participants at the time.

4.12.iii Indexing

Following the development of a framework, the data is indexed according to the corresponding theme. This helps the data to be analysed by identifying the themes within the data. This was completed with the interview transcripts, and allowed the framework to be applied directly to the data gathered. During this stage, the key themes in the framework were identified within the transcripts. This was not an easy task as some of the comments within the transcripts could be placed under several themes. Careful analysis of the statements within the interviews was required to ensure that the data was assigned to themes which remained true to the experiences of the participants. This was essential to ensure the phenomenological focus was maintained.

4.12.iv Charting

After the themes are identified within the texts, charts of themes are created (Srivastava and Thomson, 2009). This allows the data to be lifted from within the transcripts to allow for easier identification and comparison. This allowed the data to be collected together and presented in the thesis more easily.

4.12.v Mapping and Interpretation

The final stage involves the analysis and interpretation of the data. It is important that this analysis reflects the attitudes, beliefs, and values of the participants in order for any recommendations or strategies arising from the research to be genuine and true (Srivastava and Thomson, 2009). This was an important element of this research, given that a phenomenological approach was taken. It was essential that the analysis echoed the experiences of the participants, and that the outcomes of the research reflected this appropriately. This was further assisted by the time spent familiarising myself with the participants when not actively researching their experiences. Additionally, awareness of my own thrownness and situatedness within the research process and lifeworld of others helped to reduce my own influences on the analysis of the data. This is discussed in Chapter 17, where my own influences are considered and discussed. It should be noted that hermeneutic phenomenology acknowledges that a completely unbiased approach to analysis is impossible, and that the use of reflexivity is crucial to the trustworthiness of the research as this allows the identification and exploration of any biases and helps the researcher to avoid distractions (Neubauer et al., 2019).

4.13 Methods Summary

This chapter has outlined the ontological and epistemological approaches used within this research. A phenomenological approach to the research was used in order to ensure that the person remained central to the research, and the focus did not become about the dementia. Observations and interviews were used to gather data from the participants, with care taken to ensure that the correct meaning was understood, especially taking into consideration that some participants had difficulty expressing their thoughts at times.

Careful consideration was given to the ethical issues which arise from carrying out research with people with dementia, and further detail of these considerations can be seen in Appendix 3, which is an article published from this work detailing the factors which should be considered when involving people with dementia in research. This included gaining ethical approval from the university, consent, assent and dissent, and ways in which information could be provided that would be as easy to understand as possible. Care was taken to ensure that care givers were made aware of the research where applicable, and the wellbeing of participants during observations and interviews was considered at all times.

Following the data collection, detailed analysis occurred to identify themes according to the remit of the research, which was to determine whether the Occupational Engagement Framework was applicable to the participants of this study. The themes which arose are discussed in Chapters 7-9 in detail, and further analysis of this follows to provide an understanding of occupational engagement for the participants of this research.

5. Authenticity and Trustworthiness in Phenomenological Research

Qualitative research methods, such as those used in this research, are valuable in gaining an insight into the experiences of others (Shufutinsky, 2020). However, these approaches are based within interpretivism, which means that the results are dependent on the researcher and the participants involved, and therefore the data and the perspective of the researcher will be unique to that study (Labianca et al., 2000; Shah and Corley, 2006). This means that the analysis of data in qualitative studies should be judged on the ability to provide a credible insight into a phenomena which has been developed through interpretation of the experiences of the participants (Shah and Corley, 2006). It is argued that the bias of the researcher, which is shaped by their own personal experiences and situation, can heavily influence the interpretation of data, and rigorous and methodical strategies must be employed by the researcher to minimise this and develop a credible argument (Nowell et al., 2017; Shufutinsky, 2020).

The phenomenological approach used within this research was chosen because of the focus on individuals' life experiences, aligns with the person-centred focus of dementia care. In order to evaluate the data arising from the experiences of the participants, thematic analysis was used to identify themes and develop an argument for the development of a new framework to help therapists understand occupation for people with dementia. Both of these approaches are fraught with interpretation of the experiences of others, leading to a potential question over the authenticity, trustworthiness, and credibility of this research. This chapter explains the processes which were employed to reduce researcher bias and to ensure that the resulting argument holds integrity.

Picton et al. (2017) argue that the old adage 'nothing about me, without me' should be applied to research, especially in health care related research. That is, the experiences of individuals should be considered and represented in order to inform and develop health care practises, as opposed to relying on the opinions and beliefs of those who have no direct experience of the phenomena. Phenomenological research is well positioned as a methodology to capture and portray the experiences of individuals, giving them a voice (Slade et al., 2012; Byrne et al., 2013; Picton et al., 2017). The aim in using phenomenology as the methodology within this research was to provide an opportunity for the participants (i.e., people with dementia) to share their experiences of occupation. The very nature of phenomenology is subjective, and therefore a positivist perspective of reliability and validity should not be applied (Englander, 2012). Picton et al. (2017) argue that one of the ways that researchers can increase the transparency of their research is to ensure that the methodological approach is congruent with the methods chosen, and that this is consistently reported and applied throughout the research. The phenomenological approach to this research was held at the forefront of all elements of the process: the methods chosen, research design and interpretation of data were all developed with the person in mind, ensuring that optimal opportunities were made available to participants so that they could share their lived experience and ensuring that their experiences were reflected in the emerging theoretical analysis.

Furthermore, hermeneutic phenomenology recognises that the interpretations of the researcher are as significant as the descriptions of lived experience provided by the participants, allowing the researcher to apply their lens to the data to construct meanings which are both credible and faithful to the participants (Risser, 1997; Dangal and Joshi, 2020). This approach allows the researcher to interpret the data using previous knowledge and theories, with findings becoming a shared understanding of reality between the researcher's perspectives and text (Dangal and Joshi, 2020). During this research, after the themes had been identified from the transcripts and the observations, interpretation was carried out using the experiences of the participants but also drawing on knowledge previously gained from studying occupation and people with dementia, and were later checked against existing theories and research to ensure that interpretations were in keeping with previous findings (but allowing any new findings to develop accordingly). These were then used to construct a framework which demonstrates a new understanding of occupation and dementia which reflects the experiences of the participants and also the existing knowledge if this area of practice.

In order to strengthen the position of this research, it was necessary to address trustworthiness. This is also known as truth-value, i.e., the truth of how the participants experienced the phenomena, and is said to be the equivalent of internal validity in quantitative research (Korstjens and Mosa, 2018; Dangal and Joshi, 2020). Lincoln and Guba (1995) suggested the following strategies that can be employed by researchers to increase the trustworthiness of their research: credibility, transferability, dependability, and confirmability.

Credibility addresses the fit between the views and experiences of the respondents and the researcher representation of these (Tobin and Begley, 2004). Lincoln and Guba (1995) suggested that this can be achieved by prolonged engagement, persistent observation, triangulation, and peer debriefing. For the purposes of this research, prolonged engagement and persistent observation were carried out, with weekly visits to the centre occurring over approximately 10 months so that the participants experiences could be more fully understood and represented in the research. This allowed time to get to know the participants and to develop a deeper understanding of their current situation and life experiences. The time spent at the centre was also time spent observing the participants in activities at the centre, which also allowed triangulation in the interviews where participants were asked to describe their experiences and checks were made about the understandings I held about these. Peer debriefing was not possible during this research as there was no other researcher involved. It was considered that asking the participants to review the interpretations of the data would have been valuable, however it was acknowledged that they would be unlikely to recall the experiences and activities that they were describing at the time of the interviews and observations by the time the analysis was complete. However, in order to overcome this, checks were made during interviews to ensure that my understandings were correct to alleviate any misrepresentation of their experiences.

Transferability refers to the generalisability of the research to other areas (Lincoln and Guba, 1995). It is acknowledged that the researcher cannot predict where the research might be applied or transferred to, however the research can assist with this process by ensuring that rich descriptions are provided which would allow others to judge whether the findings can be transferred successfully to other areas (Lincoln and Guba, 1995). Throughout this research, descriptions have been provided to allow the reader to gain a deeper understanding of the decisions made and reasons for this, and of the interpretations of the data. Examples of the data have been provided to strengthen the argument of the interpretation and to illuminate the research findings. It is hoped that these would allow others to gauge whether the findings would be applicable to another area of practice.

Dependability (or consistency) relates to the presentation of the research in a way which allows the reader to fully understand and examine the research process (Lincoln and Guba, 1995). In order to meet this criteria, the research must be presented in a way which is logical, traceable and be clearly documented (Tobin and Begley, 2004). The thesis provides a thorough description of the processes involved in this research and the decisions which were made in a logical manner. It is hoped that this provides the reader with an understanding of the whole research process so that the trustworthiness can be evaluated.

Confirmability is the process of establishing that the interpretations and findings are true representations of the data and are not merely derived from the imagination of the researcher (Tobin and Begley, 2004; Korstjens and Mosa, 2018). In order to fulfil this condition, researchers must demonstrate how conclusions and interpretations were reached, including markers for theoretical, methodological, and analytical choices throughout (Koch, 1994; Tobin and Begley, 2004). This also provides an audit trail by providing a clear rationale for and evidence of the decisions and choices made by the researcher (Koch, 1994).

One of the key ways of achieving this is by participating in reflexivity (Tobin and Begley, 2004). Reflexivity allows the researcher to be self-critical, accounting for the research process and acknowledging the internal and external dialogue that occurs (Tobin and Begley, 2004). Lincoln and Guba (1995) suggest that a reflexive diary is kept by the researcher to document daily logistics, methodological decisions, and rationales, and also to reflect on the personal values, interests and insights relating to the research. Throughout this research, a reflexive diary was kept in order to help in this process and to capture importance influences on the research. This helped to identify any potential bias within the research in relation to the experiences of the participants, allowing me to separate this from my own personal lived experience and that of the participants.

The reflexive diary allowed me to document thoughts, attitudes and preconceptions as the research progressed. Not only is this an excellent way of keeping track of the 'light-bulb' moments, but it allowed reflection on reading material, the research process, and interactions with participants. Reflexivity is considered to be an important part of research, allowing the researcher to reflect on the research process and their effect on it. It is a way of the researcher:

> *"turning the research lens back onto oneself to recognise and take responsibility for one's own situatedness within the research and the effect it may have on the setting and people being studied, questions being asked, data being collected and its interpretation"*
>
> (Berger, 2015 p. 220)

To this effect, being reflexive is an essential step in the researcher recognising that they influence all elements of the research, including the data analysis. Personal acknowledgement and understanding of how a researcher potentially influenced the study adds credibility and trustworthiness to the research (Scott, 1997; Alvesson and Skoldberg, 2000; Berger, 2015). This is especially important in qualitative research where there is a difficulty in proving the validity and reliability of the data, which is much more suited to quantitative studies

(Curtin and Fossey, 2007). The diary was used as a way of reflecting on my own personal experiences and thoughts, and was written in the first person. It was used to examine important events throughout the research and as a means of examining these more closely and identifying the learning from this (Institute for Advanced Teaching and Learning, 2015). The reflexive diary was completed on a regular basis, but especially after contact with participants. In addition, the diary was used to help identify ways in which my own preconceived attitudes and beliefs and experiences affected the research, and vice versa. This was especially important because some of the reading completed around self and dementia, and some of the experiences of the participants, were particularly upsetting to me personally, and it was important that this was used constructively and examined to understand the effect of these and to ensure that this did not influence the research to the detriment of the experiences of the participants or data analysis.

In addition to the reflexive diary, details of each encounter with the day centre and participants were recorded. This was a great way of documenting what happened at each meeting, and of capturing the details of conversations, behavioural elements of the encounter and any initial thoughts and feelings on what happened. Examples of the reflexive element of this research can be found in Chapter 17, which details some of the issues that arose during this research.

The process of ensuring authenticity, trustworthiness and credibility can be difficult in qualitative research, especially in that which seeks to capture and interpret the experiences and lifeworld of an individual in relation to a particular phenomena. It can be fraught with challenges to ensure that the researcher does not over-influence the interpretation, making sure that the findings reflect the experiences of the participants. However, the application of the strategies described here ensures that the lived experience of the participants remains at the centre of the research and therefore increases the authenticity and trustworthiness, and therefore its value to the future practice of therapists.

6. Case Studies

This chapter provides a general introduction to each participant and an initial analysis of the observations and interviews for each, identifying the main themes that emerged from the research for each. The themes were identified in relation to the Occupational Engagement Framework to help establish whether the framework can be applied to people with dementia in a day unit setting. A cross-case thematic analysis then follows. Please note that, in keeping with the ethics guiding the research, the dementia diagnosis of each person is only known where they have disclosed it. The case studies include information that was given by the participants during interviews and conversations over the course of the research. The images were chosen to highlight and illustrate the most valued occupations for each person at the time of the research.

6.1 Fran – Self-Image and Occupational Accomplishment

Fran is a 62-year-old lady who has been diagnosed with young onset Alzheimer's disease. She has previously worked in an administration role within the NHS and retired several years ago. Fran is very positive about living with dementia and tries to overcome the difficulties she faces; however, she also struggles with severe arthritis which has a major impact on her daily life. Fran is married with gown up children, and is very family focussed, having strong relationships with her siblings and daughter in particular.

6.2 Brian – Creativity and Overcoming Challenges

Brian is an 86-year-old gentleman who has been diagnosed with dementia. He also has significant physical problems which affect his mobility and continence, and which have a major impact on his daily life. He is married with grown-up children. He lives with his wife and his 94-year-old father-in-law, for whom he built an annex onto his home so that he could live with them but still remain independent. Brian has been an active man throughout his life, working in the building trade. He has built several houses during his lifetime, and he currently lives in a house he built especially for himself and his wife. Brian is very proud of his past achievements and enjoys talking about these.

6.3 Sally – Identity and Anxiety

Sally is a 78-year-old lady who lives alone. She has 2 supportive daughters and a partner. Previously Sally was a keen seamstress and enjoyed making garments for herself and others. Sally has a diagnosis dementia and also experiences high levels of anxiety and low mood and has mobility and chest problems. At the time of the research, Sally was in the process of moving out of her family home and was finding this particularly challenging.

6.4 Peter – A Spiritual Journey

Peter is in his 70's who is known for dress in a shirt and tie at all times. He has vascular dementia. Peter is a very religious gentleman who states that the Church is his life. He feels that Christianity has guided him throughout his life. Previously, Peter worked in a manual job. He also worked as a lay chaplain and has spent many years visiting the community and doing charity work. For a while he worked in the local prisons, where he gave advice and worked alongside the prisoners to give spiritual guidance. Peter is now retired but remains involved with his local church. He currently enjoys colouring the mindfulness patterns, and he buys frames from a local charity shop and frames his pictures so that the centre can sell them and raise funds. It should be noted that Peter had difficulty with verbal expression and did have difficulty engaging in the interviews. As such, some of his responses are not always clear and required further interpretation.

6.5 Ethel – Loss, Grief, and Loneliness

Ethel is a lady in her 80's who has dementia and breast cancer. She also has some mobility problems and experiences anxiety and low mood which impact on her daily life. Ethel is a very lonely lady, whose husband and one of her sons have died. Although she had many job roles in her life, her favourite was running a wedding boutique. Ethel's other love in life is sport, in particular cricket and football, and her favourite footballer is Wayne Rooney!

6.6 Tony – Determination and Perseverance

Tony is an 81-year-old gentleman who has vascular dementia. He lives with his wife and has a life-long interest in radio broadcasting, using morse code to communicate with fellow broadcasters all over the world. Tony also enjoys bird watching and fishing. He had a stroke approximately 4 years ago, and the effects from this had a significant impact on his memory, physical abilities, and speech. Tony also described how he was diagnosed with depression, and although he didn't recognise it as this at the time of diagnosis, he states that the treatment has definitely helped him. Tony is very positive in his outlook and tries to overcome his difficulties.

Now that I have briefly introduced the participants of the study, I will examine their experiences of occupation as they described it in their interviews and in terms of what was observed during the sessions at the centre. Initially, this is discussed using the original framework which was proposed by Morris (2012), and further developments to the original framework are discussed which allow a deeper understanding of the process of occupational engagement for these participants. The occupations which the individual were observed to participate in and which they chose to discuss are evaluated in line with the framework. This is to ensure that those occupations which are most (or least) valuable to the *individual* are considered, in line with the person-centred, phenomenological approach to this research. This ensures that the lived experiences of each participant are appreciated and adds value to the conclusions drawn.

7. Analysis of Experiences Using the Original Occupational Engagement Framework

In order to investigate the application of the Occupational Engagement Framework to the participants of this study, the data were initially analysed using the conditions of the original framework. During the process of identifying themes from the data, the framework was applied to occupations that the individual currently participated in, but was also considered in relation to the consequences of non-participation. This differed slightly from the original research by Morris (2012) as the reasons for not participating were largely because of a change in ability (physically, mentally, or cognitively) and not usually because a choice had been made. The consequences of non-participation were considered to be important to the participants of this research, mainly because the consequence had a negative impact on their self-identity, and in some cases caused a further deterioration in mental health.

7.1 Participation in Occupations Which Hold Personal Value

In the original Occupational Engagement Framework, Morris (2012) stated that participation in occupations was the entry point to the framework. It was argued that participation holds a neutral value, but that there are other more positive or negative values that the occupation may hold for the individual. The original research denotes that occupational engagement is positioned as holding a more positive value. The Occupational Engagement Framework also places importance on the consequences of participation in an occupation, stating that consequences can be positive or negative and that these may also affect the overall experience of the occupation, regardless of the value.

Below, I discuss some of the experiences of participation in occupation that were described by the participants. This process was important to hear the factors that affected the process of occupational engagement in order to identify areas that supported the Occupational Engagement Framework, or which would suggest a difference in how this would be presented for people with dementia.

Fran provided examples of occupations with positive and negative value during the interviews and whilst being observed at the centre. Much of her time in the interviews was spent talking about her appearance and how important this was to her. She spoke about her clothing, makeup, and hairstyle at length, and how the occupations related to this were very valuable to her, and participation in these was positive. In applying the original framework to this, we can begin to see how this approach would work for Fran.

Applying makeup was identified by Fran as a valued occupation. She participates in this on a daily basis, and therefore we can apply the framework. The occupation itself holds positive value, and as Fran describes it, we might say that it was an absorbing occupation. The consequences of this are positive as Fran stated that she feels more confident when she has makeup on. Similarly, the same is true for getting dressed: Fran stated that she likes to be dressed smartly and this can be an absorbing occupation for her. This has become more absorbing for her following her diagnosis of dementia and development of arthritis as she now needs to consider clothing that will not cause her pain (e.g., shoes) and which complement each other. The consequences of this are variable: Fran described how she feels a greater sense of wellbeing when she looks good, but also described the negative consequences from this when she does not achieve the appearance she wanted. Also linked to this was shopping for clothes and makeup. Fran described these as occupations with a positive value, and as engaging occupations (possibly absorbing). Fran’s participation in this is limited now as she can no longer drive, and her most frequent opportunities to participate in this are at the supermarket. The value of this was again positive for Fran, however her description of events whilst shopping indicate that this can sometimes be an engaging experience (when she is able to find her way around and pay for items) or it can be a disengaging experience if she is disorientated and cannot find her way around the store. For Fran, the disorientation is not a consequence of the occupation itself, it is sometimes related to the environment (e.g., if the store layout has changed) or it can be related to her cognitive impairment. The consequences of this occupation very much depend on whether the value was positive (engaging) or negative (disengaging), with the former providing positive consequences of a sense of achievement and wellbeing, and the latter generating negative consequences including reduced confidence and a sense of failure.

At the centre, Fran was observed to participate in a range of occupations. These included art and craft, knitting, baking and quizzes. Fran described how she found many of the art and craft groups to hold positive value. She was observed to be engaged and at times absorbed during the sessions, indicating that these occupations held positive value. Fran described the consequences as positive too, increasing her sense of achievement and wellbeing.

However, one art session involved drawing stars for a display at the centre. Fran was observed to be disengaged during this session and later described this as being a difficult session which was low in value for her because she found the stars difficult to draw and did not consider herself to be good at drawing. The lesser value of this occupation was related to the occupation itself and Fran's abilities to participate in this occupation at a level which was satisfactory to her. The consequences of this were a sense of failure and feeling that she was unable to complete a simple activity that everyone else in the group was able to do. The original framework would state that this was a disengaging occupation for Fran, and that occupational engagement had not been achieved. However, Fran was very much engaged in the occupation, trying her best to achieve what others in the group were doing, although the value of the occupation was negative.

Fran particularly enjoyed the baking at the centre. These sessions varied for Fran: at times the baking was an interesting occupation, and at other times it was engaging. The consequences were the same regardless of the value: increased sense of achievement and wellbeing. She also participated in knitting. This was observed to be an absorbing occupation for Fran, and she reported positive consequences from this.

As a therapist applying the framework to Fran, we can establish the occupations with higher positive value at the centre and can use this to encourage Fran to participate in similar activities at the centre whilst avoiding occupations with a negative value and/or consequence, and also to incorporate these into her home life in order to achieve a greater sense of wellbeing (Morris and Ward, 2018).

Brian also spoke in detail about his current occupations, and those which were the most important to him were singing and art. Brian attended art and singing groups on a weekly basis, and he spoke about these during the interviews. He was not observed in these occupations as they occurred outside of the centre, however he was able to provide detail about these and from this the value was established. When discussing the art groups, Brian spoke in immense detail about the work that he was doing and the effects he was trying to achieve on his pictures. He brought some of his pictures to the centre to show me. From this information, we can assume that the art was an absorbing occupation for Brian and therefore of positive value. The consequences from this were also positive, and it was clear from his descriptions that the process provided him with a sense of achievement and wellbeing. Brian spoke about the singing for the brain group that he attended. His conversations about this were not as detailed, and therefore this was presumed to be an engaging occupation for Brian (again, no objective value could be established therefore this is subjective from Brian's descriptions). Again, this is a positive value (but not as positive as the art) and provided him with similar positive consequences. At the centre, Brian was observed to participate in cooking sessions. The observations and conversations around these occupations positioned them as being interesting occupations, therefore of lower value that the art and singing. The consequences were not positive or negative – more neutral, although he did like to take his wife something home to eat. As a therapist working with Brian, this might suggest that occupations linked to music and art would hold a greater value for Brian and would produce more positive consequences, leading to an overall greater sense of wellbeing.

Sally was a little different when speaking about her valued occupations. She was, at the time of the interviews, physically unwell and was being cared for by her daughters. As a result of this, her participation in valued occupations was limited. Her daughters were performing all of her activities of daily living on her behalf, and the main occupations that she participated in were at the centre. Of the occupations she participated in at the centre, Sally spoke most about sewing and knitting. Sally was observed to participate in both of these occupations at the centre, and the value of these varied. On some days, the sewing and knitting were observed to be interesting occupations, on other days indifferent. On some days, Sally stopped participating after a while. This indicates that the value of the occupations fluctuates from day to day. Sally spoke about experiencing some pleasure from participating in these sessions, indicating that there was a positive consequence from this. As a therapist this would indicate that these occupations were not high value for Sally and that other occupations should be investigated in order to help her achieve more positive consequences and therefore a greater overall sense of wellbeing.

Peter had difficulty expressing his thoughts during the interviews because of the effects of his dementia, however he was able to provide some information about his experiences. Observations were used in addition to this to help understand his occupational engagement. Peter spoke about watching television during the interviews. This was also observed during the sessions at the centre. During the session at the centre, this was observed to be an indifferent occupation for Peter and did not provide any particular consequences for him (positive or negative). When we spoke about it, he stated that he only finds an increased value in watching certain kinds of television programme. When he is watching his preferred programmes, he finds them interesting and there are some positive consequences from this. He spoke about how he had asked his wife to stop watching certain tv programmes (such as the soaps) as he found these repulsive and they made him feel angry and undermined his Christian values as a consequence. Peter also spoke about how he enjoyed colouring in pictures and bringing these to the centre for them to sell to raise funds. As with Brian, Peter brought some examples to the centre to show me, and described in detail how he colours the images (examples of his work are used within the chapters of this thesis). It was assumed from his descriptions of the work that this is an absorbing occupation for Peter, and he found positive consequences as a result, including a sense of accomplishment and wellbeing. Peter also spent time away from the centre searching charity shops for second-hand frames in which to display his work. Whilst this was knowledge gained from staff and not Peter himself, this can be used within this context as an occupation with a positive value and positive consequence.

When observing Ethel at the centre, it became very clear that many of the occupations offered were of a lower value and provided more negative consequences than for the other participants. Ethel was observed to participate in a reminiscence session at the centre. She clearly found this a disengaging occupation and sat with her eyes closed throughout making negative comments. Following the occupation and in discussions later, Ethel stated that the occupation had resulted in negative consequences and had significantly affected her mood. This was similar for a ‘pets as therapy’ session at the centre. Ethel was observed to find this a repulsive occupation and made rude comments about the dog and refused to touch it. Later in the interviews, Ethel confirmed that she had found this a repulsive occupation because although she liked dogs, she did not like this particular breed of dog and that she had found no positive consequences from participating (although did not describe any negative consequences). This demonstrates that every occupation is unique: a different breed of dog might have evoked a different response from Ethel, and she may then have found this a more engaging occupation. Ethel was also observed to participate in knitting at the centre. She was observed to find this an interesting occupation, although the consequences were negative in that she found it frustrating because she found the stitches difficult and was not able to complete them to her previous ability. In looking at the application of this as a therapist to Ethel’s occupations, it is clear that those occupations observed at the centre did not support Ethel’s wellbeing, and alternative occupations which were higher in value and produced more positive consequences should be sought.

Tony meanwhile, explained that he had a diagnosis of vascular dementia following a cerebro-vascular accident (CVA). Tony spoke about his current occupations, although his participation in some was limited following his CVA for his own safety. The main occupation Tony spoke about was radio broadcasting. He had recently re-learnt this after forgetting the codes following his CVA. Tony described this as an absorbing occupation and talked about how he had friends across the globe that he spoke to regularly. The consequences of this occupation were very positive for Tony. It provided pleasure and enjoyment, kept him in touch with friends, and provided a sense of achievement and wellbeing (especially after re-learning it). Tony also spoke about an exercise group that he attended to help with his mobility following his CVA. He described this as an engaging occupation and stated that the consequences were positive because it helped him to remain physically active and also provided him with a sense of achievement and wellbeing. At the centre, Tony was observed to participate in a number of sessions, including art and craft and cooking. Both of these occupations were observed to be engaging and at times absorbing. Tony stated that both of these occupations were new to him and that he was finding them both interesting, and was finding pleasure in learning something new. He also enjoyed being able to take his wife home tangible items (whether that was food or an item he had made). Again, as a therapist applying the occupational engagement framework, this allows us to clearly see that the occupations described by Tony provide a sense of wellbeing and should be harnessed so that overall his wellbeing is maximised.

Tony was a very interesting gentleman in terms of his perseverance in participation in occupations with a high value. For Tony, his main pleasurable occupation was his radio broadcasting. This was an occupation that he began in his career in the forces, where he would broadcast the weather forecast to ships on the ocean, but which also later became a much-loved hobby. This occupation is very skilled and requires knowledge of coding which is played out across the airwaves to communicate with others. Tony participated in this throughout his life, entering competitions and forging friendships with others across the world. For Tony, this was an absorbing occupation and one in which he found a lot of pleasure. What was most interesting was that when Tony had his cerebrovascular accident (CVA or stroke), he forgot the coding that is required for communicating over the radio. Because this is a very valued occupation for him, he spent months re-learning the code so that he could continue to participate in this occupation, and at the time of the interviews he was again communicating with friends in other countries on a regular basis. This persistence demonstrates the value of this occupation to Tony and is testimony to the positive consequences he must experience as a result of participation.

7.2 Evaluation of the Application of the Original Occupational Engagement Framework

Applying the original framework to people with dementia in a day centre setting allows us to identify which occupations are most valuable and allows the examination of consequences to identify which occupations provide the greatest positive value with the most positive consequences. These can be harnessed and focussed on to allow the maximum opportunity for wellbeing over a period of time. Following the initial analysis of data using the Occupational Engagement Framework as an a priori structure for the themes, a second analysis occurred to identify themes which might not fit with the original framework, or which might identify a new understanding. This analysis was enlightening and allowed the true experiences of the individuals to emerge from the data.

In immersing myself further into the data and allowing new themes to emerge, several interesting points arose which suggest an argument for further development of the framework. The original framework is schematic, and whilst this allows it to be easily applied across a range of different occupational contexts, it became clear during this research that a detailed understanding of the value of the occupation, the factors affecting participation and a further analysis of the significance of the consequences of participation for the participants of this study might provide a more in-depth understanding of occupational engagement. This will allow the therapist greater insight into ways in which occupational engagement can be maximised to incite the utmost possible sense of wellbeing. In the following chapters, I will explore the aspects of what this more detailed understanding would entail, and its implications for the framework.

8. Moving Towards a New Occupational Engagement Framework: Initial Analysis and New Understandings

This chapter focusses on the elements identified by the participants in their interviews which affected participation and engagement in occupations, and which suggest further development of Morris' original framework might be helpful to therapists. The new arguments are presented with supporting examples, and a revised framework is presented. After this follows a re-analysis of the overall occupations discussed by the participants which was presented earlier.

8.1 The Occupational Engagement Framework: Rethinking 'Value'

The Occupational Engagement Framework states that occupational engagement is the process of participating in occupations (activities) with a positive personal value. Within the framework are a range of states which demonstrate the value of the occupation to a person when participating in that occupation. The framework proposes that individuals are more likely to experience positive wellbeing if they participate in occupations which have a high value and which produce positive consequences.   The framework also makes the claim that the value of the occupation fluctuates according to a number of complex internal and external factors, and that the perceived consequences of participating in an occupation change over time.

All of the participants described occupations that held value to them both in the past and currently, and where possible continued to participate in these occupations. As my work with the participants developed, I found that the importance (personal value) of an occupation could remain high, but that the value (as defined by the original framework) could be much less. For example, a previously "absorbing occupation" which held high value to a person becomes an "interesting occupation", although the assigned value remains the same to the individual.

Not only does this raise a question around the value of the occupation and its relationship to occupational engagement, but for me, it also provided confusion around the term ‘value’ and how it is used within this framework. Additionally, changes to the value brought to light some of the key complexities around people with dementia’s sense of occupation. This points to an alternative understanding of how ‘value’ might be situated within the framework.

8.2 Reframing Value

The original framework refers to the ‘value’ of the occupation as being central to participation and engagement. In the original framework, the value is directly linked with the way in which an individual engages in that occupation e.g., do they find it absorbing, engaging, interesting, indifferent, disengaging, or repulsive. Whilst it is useful to have a graded value system to understand what is happening for an individual, it became confusing whilst applying it to the participants of this study as a more complex view of occupational engagement emerged. This became apparent because the occupations that the participants were describing were not only important, but were also *valued*: they were often intrinsically linked to the person’s life history, had meaning and, most importantly, were inherent to the individual’s sense of identity.

This understanding developed through using the phenomenological approach to the research, which aimed to gather an insight into the participants’ own lived experiences of occupation. All of the participants provided detailed descriptions of their involvement in various occupations, and spoke about the value of this to them personally. This was often linked with their self-identity. New occupations which supported their changing identities as their cognitive and physical abilities transformed were approached with enthusiasm, whilst occupations which they could no longer participate in, but which previously supported their self-identity continued to hold personal value even though they were not currently actively participating in these occupations. The original framework would support this by stating that this was non-participation, however what added to the complexity was that some participants continued to participate in personally valued occupations but under the original framework the value changed i.e., previously engaging occupations became interesting occupations. For the participants of this research, the personal value of the occupation remained the same, whereas the original framework would imply that this had changed. For the participants of this research, the personal value of the occupation was imperative to their sense of self and identity, and it was felt that this should be acknowledged in any developments to the framework moving forwards.

It would not make sense to use ‘value’ to describe two different elements of the framework, and therefore it is proposed that the term ‘value’ is assigned to the occupation in relation to the person (i.e. the value of the occupation to the individual) and that the value of participation is referred to as the positive or negative ‘intensity’. This allows recognition of the depth of involvement in the occupation itself but retains the importance of the value of the occupation to an individual.

Assuming that the value of the occupation is an attribute assigned by an individual to the occupation, it became apparent that for many of the participants there were occupations which remained high in value but which they were unable to participate in. Similarly, there were occupations which remained high in value, but the intensity of occupational engagement (i.e., absorption, engagement, interest etc) changed. As such, for some participants, valued occupations were left behind: they remained high in value, but the person no longer participated in them.   This is important for the framework to consider, as occupations which may appear to be indifferent (and therefore a lower value when the original framework is applied) may in fact be the result of more complicated interactions between internal aspects of self-identity and external factors, as well as different elements to the occupation itself which may allow for new, more achievable activities to be participated in.

8.3 Positive Wellbeing and the Impact of New Learning

All participants reported a greater sense of wellbeing when they had been able to participate in occupations which held positive value and provided positive consequences. Interestingly, for several of the participants, new learning proved to hold the most positive value. While their valued occupations reflected key aspects of their own identity, this did not limit the types of occupation to those they previously used to do.

Fran in particular found occupations which nurtured new learning to be extremely positive. Attending the centre allowed her to participate in a number of occupations that she had never experienced before. Fran experiences many positive consequences from new learning: increased confidence and self-esteem, achievement and accomplishment, positive feedback from others, challenging dementia. All of these consequences increase the value of the activity and therefore increase the chances that Fran will participate in them. Fran spoke about her sense of achievement when making tangible items that she can take home. She stated:

“I feel, “look what I’ve done!” I take photographs and send them to my sister.”

She described feeling very proud of her items and shared this with others who would celebrate her success.

Brian also reported an increased sense of wellbeing from new learning. Brian had recently begun painting classes and was attending a Singing for the Brain group. He talked in detail about these occupations, and this detail demonstrates how absorbing he finds these occupations. These were new experiences for Brian, and he found significantly positive consequences in participating. Brian likes to remain active, and these occupations provide him with an opportunity to be absorbed in something which provides pleasure, a sense of accomplishment and pride, all positive consequences. He also described that sharing these experiences with his wife further heightened the positive consequences. When talking about his painting, Brian became wholly absorbed in the conversation and provided a lot of detail about his work. This reflects the value of the occupation for Brian. During one week at the centre, he brought some of his pictures in to show me, again reflecting the value of this for him. Brian spoke about the consequences of this in terms of a sense of achievement and pride, and this was encouraged further by the praise from his wife. He stated that it feels “great” when he is able to create a piece of work and that he “loves” being able to add the intricate details into a picture. He related this to his singing of Sonny Boy, again talking about the detail and feeling that he puts into singing the song for others. He stated that he tries to “*get the expression into the song to portray the words*”, again reflecting how absorbing he finds this occupation. He went on to say:

“*You get the words of the song into your body, so that you feel it and then you can put a reaction to it then*.”

This reflects that new learning can be extremely beneficial to people with dementia. New occupations, which previously held little or no personal value to the individual, can be introduced with great effect. The positive consequences which result from this can further support an individual’s sense of self and identity (as seen with Brian when he relates his painting to his valued occupation of singing). Not only does this support the importance of consequences within the framework, but it also demonstrates the importance of finding new occupations with personal value to replace the valued occupations which can no longer be participated in. This further supports a change in the placement of the term ‘value’ within the framework, encouraging therapists to consider the introduction of new valued occupations to people with dementia which can result in positive consequences that support self-identity and therefore improve overall wellbeing.

8.4 Negative Consequential Effects and Participation

As previously noted, the points at which participants were hesitant to participate in (potentially) valued occupations revealed many of the complexities of the relationship between value and occupation.

The perceived consequences were a very important element of participation for the majority of the participants of this research. This was particularly the case where there was an element of risk: either of failure or harm. For example, Fran lacked the confidence to participate in some occupations where she perceived that she would not be successful in achieving a positive outcome. This was particularly evident in some of the occupations at the centre, for example the painting of stars. Despite it being observed that Fran's efforts were as successful as others in the group, Fran perceived that her stars were not acceptable and therefore the occupation was much lower in personal value, the intensity of engagement less, and the actual consequences were more negative (lower self-esteem, sense of failure). This was noticeable in the way she behaved within the session and particularly in her refusal of allowing her work to be photographed.

During the subsequent interviews she stated that she felt the work was sub-standard and that she had not enjoyed the group activity:

"[cutting out the stars] felt like it was the hardest thing". She also went on to state:

"I felt a bit of a fool because there were people that their dementia wasn't as bad as mine, but they were doing it ok."

For others within the study, there was a perceived consequence of harm in many occupations. For Sally, Brian, and Tony this perceived consequence prevented them from participating in many valued occupations: their physical difficulties meant that there was a risk of falling or injury, and this resulted in them avoiding the occupation altogether. Interestingly, for Sally and Tony especially, they were actively encouraged to avoid the occupation by family members who felt that the risk of injury (negative consequence) outweighed any positive consequences of participating in the occupation. Sally’s daughters ensured that she no longer had to perform any domestic activities such as cooking so that the risk of falling or knocking hot pans over was limited. Tony’s family asked him not to carry out any work in the garden or to carry out any DIY work in order to limit his risk of fall or injury. Brian self-limited his participation in occupations with a perceived risk following previous serious injury but was supported by his wife in this decision. What was notable was that the occupations that were avoided were often valued occupations and there was a negative consequence from not being able to participate, most often in relation to the sense of self as these occupations were integral to the individuals’ identity.

This highlights the importance of negative consequences on the participation in occupations. The original framework does consider negative consequences and the impact of this on individuals, however for the participants of this research they were particularly pertinent. As such, it was felt that further investigation and recognition of this was important in any developments of the framework to allow therapists to consider this more explicitly. Interestingly, the limitation of participation in occupations was sometimes imposed by others rather than the individual. What was clear was the sense of loss that arose from being unable to participate in these valued occupations, and the challenges to self-identity and wellbeing that this brought.

8.5 Value without Engagement

The original framework’s claim that value (or intensity as this has now been reframed) fluctuates according to a number of internal and external factors was evident with many of the participants. During the interviews and observations, it was noted that they were eager to participate in many personally valued occupations, but that the intensity fluctuated according to mood and physical state. However, the original framework does not easily demonstrate that the value of the occupation itself can remain high and the consequences remain positive, even if the actual intensity fluctuates from day to day or even during the occupation. This suggests a potentially different way of understanding the interdependence of intensity, value, and engagement.

Some examples. Sally often reported feeling tired whilst at the centre, and was observed on occasion to fall asleep. She stated that she found the interviews tiring and this was evident in her responses: she would begin the interviews by being engaged and providing detailed answers, but as her level of tiredness increased, she would provide less complex responses and be less engaged and interested and more disinterested. This was observed during the group activities also. Sally would begin a session by showing signs of engagement, but as her tiredness increased, she would become less interested (perhaps showing disinterest) and at times stopped participation entirely by closing her eyes.

When Fran was participating in a baking activity during her time at the centre, it was clear that baking was a highly valued occupation, and the consequences were positive in that she experienced a sense of achievement and wellbeing. However, during one baking activity she began to experience consequences of feeling tired and experienced pain from the arthritis in her shoulders. This changed the occupation from an ‘engaging’ occupation to an ‘interesting’ one, and although she continued to participate, the intensity changed: she began by being wholly occupied by mixing the ingredients and chatting within the group about what they were making, and then gradually became less involved with the physical act of baking but continued to participate by showing interest and remaining a part of the conversation about what was happening.

In a similar way, the intensity of Ethel’s participation fluctuated over time. For Ethel, this was often in relation to her mood. Over the time that she was involved in the research, Ethel was observed to experience high anxiety states on several occasions which affected her participation in occupations. She continued to participate in the occupations at the centre, but when she was in a high state of anxiety, she found the occupations repulsive at times. Ethel was observed to vocalise her dislike of the occupations and would stop participation by closing her eyes or leaving the room when they became repulsive or when her anxiety levels became too high for her to manage. Interestingly, Ethel's accounts of events indicated that the consequences of the occupation itself were not causing her anxiety levels to rise – it was because of factors external to the occupation which were preventing her from experiencing a more positive intensity from participation.

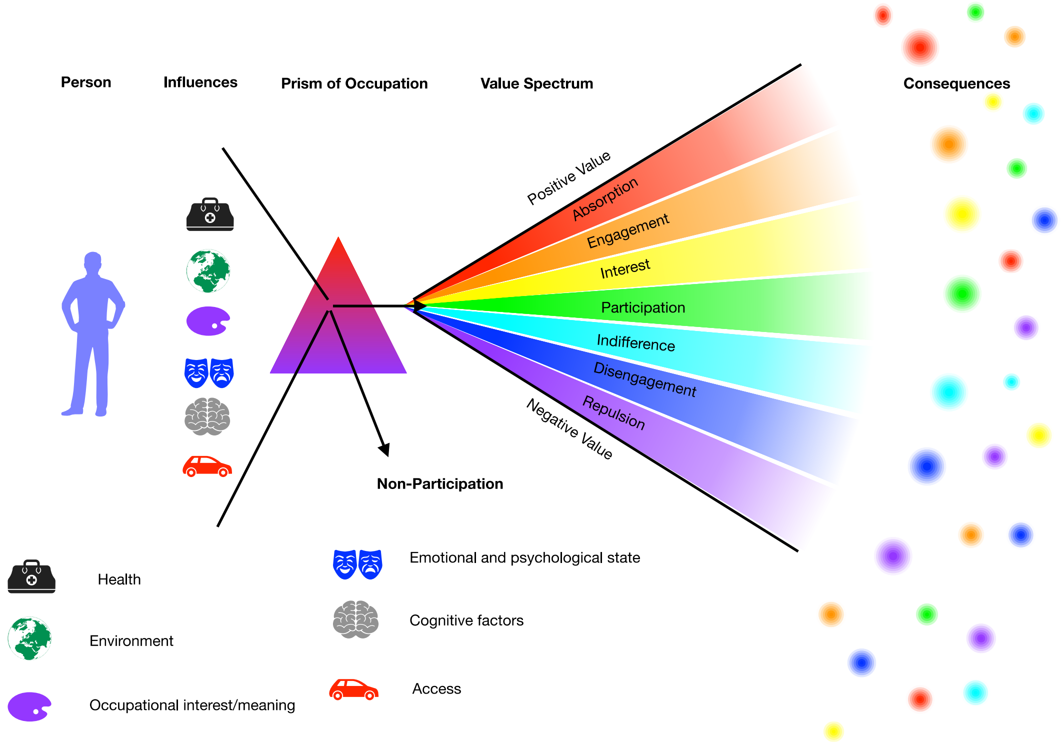
When considering this changing intensity, it is worth noting that the original framework speaks of 'perceived' consequences, which implies that a person chooses to participate in an occupation based upon what they believe the consequences will be, and what these mean to the individual. What became apparent during this research was that actual consequences are also imperative to the future participation in occupations. For Fran (as well as others), pain was a major influencing factor over whether she participated in occupations or not. This was both in terms of whether she was able to participate or not, and also the depth of intensity. This was seen within the observations, where Fran would begin an occupation and be absorbed by it. As her pain levels increased during the occupation, it would become less absorbing and more interesting. A further example would be provided by Brian, Sally and Tony: they might perceive that they are physically able to participate in an occupation and perceive the consequences to be positive, however the actual consequences might be that they experienced a fall. Furthermore, because of their cognitive impairment, they may not perceive the fall to be a negative consequence, but this might have a future impact on their health or in the limitations imposed on them by others (e.g., family). In this case, both the perceived and actual consequences provide a feedback loop which then influences a) whether a person participates in that same occupation again in the future and b) the occupation which follows immediately (in terms of both participation and the value of the occupation).

In her research, Morris (2012) also found that actual consequences influenced participation. However, in the written descriptor of the framework, consequences are noted as 'perceived'. For the participants of this research, the two elements i.e., perceived and actual consequences, were important. Perceived consequences were influential to whether individuals participated in an occupation and the intensity achieved. It is worth noting here that the very nature of dementia means that an individual's perception of the consequences may be different to the actual consequences: limited insight may mean that the full extent of the consequences of participation are not considered, or that previous actual consequences are forgotten. Actual consequences however, provided in-the-moment feedback during occupations (as for Fran with the baking and her increase in pain) which changed the intensity of participation, and also resulted in limitations to the range of occupations available to the individual. This was sometimes self-imposed, for example with Brian, but was often imposed by others (as with Sally and Tony). It was felt that this was an important factor to be included in any developments to the framework for it to truly reflect the experiences of the participants of this research.

8.6 Initial Pictorial Depiction

Figure 8 depicts the initial thoughts on how this research might change the imagery of the framework, based on initial analysis. The spectrum demonstrates the values from the research conducted by Morris and is denoted as an outcome after considering the person, influences upon the individual and the occupation itself. Consequences were shown as floating elements in the same shade as the value depicted in the spectrum. Whilst this considered many of the elements discussed by participants, it was felt that further analysis and consideration was required in order to demonstrate these complexities in a more robust manner.

Figure 8: Spectrum of Engagement (Hampson, 2021)



8.7 Summary

In examining the elements of occupational value, intensity, and consequences we can see that the relationship between these is complex and that this is further complicated by a diagnosis of dementia. The experiences of the participants demonstrates that the value of the occupation to the individual is a key factor in not only participation but also to the intensity (both positive and negative) they experience when participating. Furthermore, the consequences (perceived and actual) provide a feedback loop which influences participation and intensity both over time and in-the-moment (i.e., during an occupation). We also begin to see how these factors impact on the self-identity of an individual, and how the influence of others can support or hinder participation in occupations and the intensity experienced. The reframing of value within the framework helps to reflect that occupations with a personal value might be left behind and also that an occupation can remain highly valued, but the intensity experienced whilst participating is less positive.

This initial analysis of the data suggested that some changes were required to the original framework and that deeper analysis was required to fully understand the experiences of the participants and to ensure that any developments to the framework provided therapists with a tool to understand the factors which might influence participation and engagement in occupations for people with dementia. A deeper analysis of these factors and how they might influence/change the original framework now follows.

9. Complexities of Occupation and Dementia

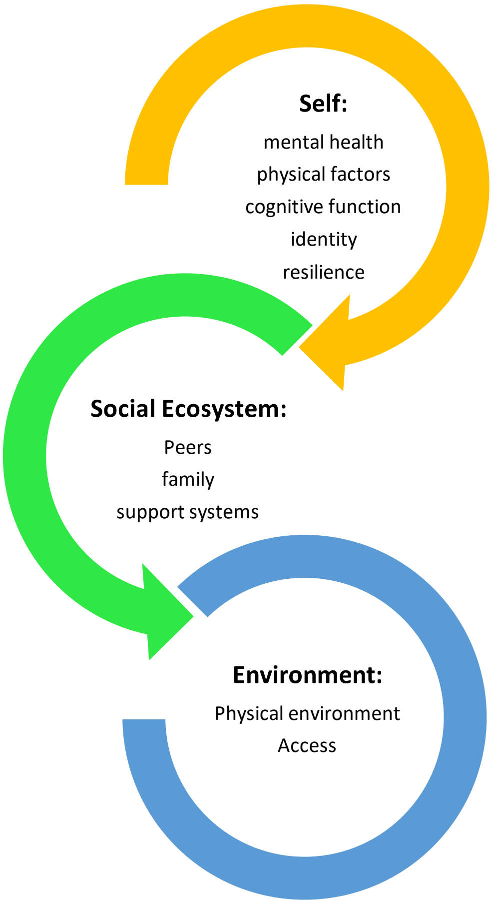
As inferred in the previous analysis, for the participants of this study, there were many factors which affected their participation in occupations. These were both internal and external, and influenced participation and engagement in occupations. The interplay of these personal internal and external factors points to the complexities of occupational engagement. Indeed, the original framework states that "complex internal and external factors" influence and effect fluctuations in occupational engagement. Morris (2012) acknowledges that the complexity of these factors was too great a topic to explore in her research, and indeed would be a whole piece of research in itself. For the purposes of this research, and to avoid any confusion about what is meant, "complex" is defined as:

> "*made of many different things or parts that are connected; difficult to understand*"
>
> (Oxford English Dictionary, 2021)

During analysis, it became apparent that these factors were absolutely crucial for the participants especially in terms of their participation in occupations. It was clear during the interviews and observations that these internal and external factors influenced participation, the value of the occupation and the perceived consequences. As such, these were explored in more depth. In beginning to understand what the internal and external factors are for individuals, this knowledge can be applied by the therapist to help the individual to overcome any adverse influences in order to facilitate participation in occupation with more positive consequences, and therefore a greater sense of wellbeing.

Over the course of analysis, three main categories were identified as being influential to occupational engagement: self, social ecosystem, and environment. Figure 9 below demonstrates the three elements identified in this research that were identified to influence the participants' occupational engagement.

Figure 9: Influences on occupational engagement (Hampson, 2021)



Each of these categories is now discussed with examples from the data to demonstrate how these impacted on the participation and engagement in occupations. This leads to the development of a new framework to increase understanding of the occupational engagement in people with dementia within a day care setting.

9.1 Self

This is a crucial element of the influences to occupational engagement, linking with the work of Tom Kitwood (1997) and Steven Sabat (1994-2005) in emphasising the importance of the individual and their experiences and life history rather than the illness itself. Both Kitwood and Sabat highlight the importance self within dementia and how supporting the individual to maintain their sense of self leads to greater wellbeing (Kitwood 1997; Sabat, 1994). This aligns with the phenomenological approach taken to the research, and ensures that the individual is considered in relation to their experiences and how this might influence occupational engagement: the value of the occupation, their willingness to participate, and the consequences achieved. The elements of self which were identified fell into five main categories:

- identity
- mental health
- physical factors
- cognitive function
- resilience

These were specific to the participants of this study, but are main elements which could be applied to a wide range of individuals with a number of physical and mental health difficulties. Each category is now examined further in relation to the participants of this research.

9.1.i Identity

The notion of self was a very important factor for all participants. Fran spoke a lot about her appearance, and this was a constant theme throughout her interviews. The changes to her ability to get out and buy herself clothes and makeup affected her self-identity, which in turn affected her mood and her participation in other occupations.

Similarly, Sally found her identity being challenged: she began to need a walking stick which she felt made her look and feel old. Although the walking stick initially challenged her self-identity, eventually it helped Sally to maintain her sense of self by allowing her to participate in occupations that supported her identity:

"I got this stick from the hospital when I had this one done. I had to walk around with it to steady myself. I felt embarrassed at having to use the stick…. I didn't want it. It makes me feel old and I didn't want to feel old. Anyway, now I'm proud I've got the stick cos it helps me to walk."

Brian spoke a lot about his past occupations in relation to describing himself, therefore demonstrating that his engagement in particular occupations identified him as an individual. His inability to participate in these occupations was a challenge to his self-identity, and this caused him to experience negative emotions as a result. Brian spent a lot of time describing in detail his past achievements. He spoke about his time in the army, his building work, and the time he spent as a bodybuilder. Brian used these conversations to project his self-image, and his perfectionism for everything he did. This was a very significant element of the interviews for Brian, as he was keen that he presented his past identity in addition to his present identity. He spoke with pride about his past work on his home, and stated that:

"I like to look outside the window into the garden and see what I've done there, and that cheers me up."

This reminder of his previous capabilities and achievements instils a sense of pleasure and pride in Brian and allows him to connect with his previous self-identity. Brian expressed this during one interview and stated:

"You know, you don't want to feel like when you walk into company, "Oh here comes that smelly old fella," or something like that. You want to feel proud of yourself and try and present yourself well."

"I've always tried to…. even though I'm how I am, as I am, I always try to keep myself clean and tidy. Because it doesn't take, doesn't cost much to do…. So you can keep yourself looking tidy. And that gives you something to do."

In this comment, Brian is trying to describe how he wants to remain proud of his achievements and present himself well outwardly to others. He described how keeping yourself clean and tidy is an occupation (something to 'do') and that for him it is a higher value occupation. During our conversations, Brian repeatedly promoted an image of himself that celebrated his past achievements as well as the most recent ones, rather than dwelling on his poor physical health and memory impairment, demonstrating that his self-image and identity remains important.

Whilst Peter was not able to express much around his occupational engagement, he did speak about his religious beliefs, and these had been a huge part of the occupations that he had participated in previously. At the time of the interviews, he spoke about how he had helped another attendee on the bus by giving her words of spiritual guidance, and he spent much of his time colouring pictures and framing them for the centre to sell to raise money. This was a way of continuing his Christian beliefs in helping others and was key to his participation in occupations. Peter also declined to participate in one activity at the centre (and others at home) because it did not align with his beliefs and values. He described how this was also the case in his home life with his wife:

"Here Theresa, come here. Now look down this street…can you see anyone going next door to his wife? She said, "No." And I said, "Well we don't watch it again and we stopped watching it for ten year. Aye. But that were it. That's the way people will live, but it's sad. Sometimes we have to put a stop to it. We don't live that way."

Ethel also found challenges to her self-identity difficult, and this too affected her mood and willingness to participate in some occupations. She had identified as a mother and wife foremost, and the loss of her husband and one of her sons was a huge challenge to her self-identity. Ethel spoke about some of her previous occupations in relation to her self-identity: for example, she previously found knitting an absorbing occupation, however once her children no longer needed the garments, this became an occupation that she no longer participated in. She described how she required a purpose for participating in occupations:

"Oh yeah, not just knitting for knitting's sake. It's exciting, you know, seeing it grow and making it up and seeing it worn. I enjoyed knitting…. REALLY enjoyed it."

This loss of role and loss of loved ones was very important for Ethel and her participation in occupations at the centre. In particular, she spoke about a reminiscence group activity where they were discussing holidays. For Ethel, this was a repulsive occupation and she eventually stopped participating because she found it so distressing. In the interviews she spoke about how the activity made her think about all of her lovely memories whilst she was a mother and a wife, and this caused her distress because she knows she will never have those experiences again.

These examples demonstrate the centrality and interrelatedness of self to occupation. Occupations define who we are (Dickens and Hampson, 2011) and we choose to participate in occupations which express our individuality. This helps to strengthen our self-identity and when we are no longer able to participate in these or we no longer have a reason to participate (as for Ethel), self-identity is challenged and is at risk of being eroded. Given the challenges to identity that dementia itself brings, the need for occupations which support this become even more crucial.

9.1.ii Mental Health

Mental health is a very important factor with regard to participation in occupation. For most of the participants, mental health was an element which influenced their willingness to participate and the intensity experienced. Most significantly, mental health was found to be an influencing factor for the participants of this research. Analysis of the data provided by the participants indicated that mood is interwoven with self, social other and environmental factors, with each affecting the other. This places mental health as a key component of internal factors, and demonstrates the importance of this when considering participation in occupations.

9.1.ii.a Low Mood

For Fran, Sally and Ethel, low mood was a particular factor. All discussed how they felt low in mood, and were emotional and tearful at times during the interviews. They described how when they were low in mood, they were more reluctant to participate in occupations. This was also noted in the observations, in particular for Ethel and Sally: on some days they were very tearful and preoccupied with events which had affected their mood, and this reduced their ability to participate in the occupations at the centre. However, all of these ladies spoke about how participating in occupations and the centre had helped to lift their mood as a direct consequence, and spoke about the long-term effect of this which made it more likely that they would participate in occupations outside of the centre.

This serves to demonstrate how crucial it is for mood to be explored by therapists when considering participation in occupations. The reluctance to participate in occupations when low in mood is counter to the fact that participation in occupations can improve mood. Participants spoke about the importance of valued occupations in relation to mood and increased willingness to participate, which further supports the need for people with dementia to have access to valued occupations with positive consequences as an opportunity to improve mood.

9.1.ii.b Anxiety

Sally was also experiencing anxiety which was having a significant impact on her ability to participate in occupations. Again, Sally stated that she and her family had noticed improvement since her attendance at the centre, demonstrating that participating in occupations with positive consequences was particularly helpful in improving wellbeing.

9.1.ii.c Motivation

For the purpose of this research, motivation is described as:

> *"The feeling of wanting to do something, especially something that involves hard work and effort"*
>
> (Oxford University Press, 2021)

Motivation was a significant factor for the participants of this research. Many were well motivated to participate in occupations, but also spoke about times when they were not motivated.

Interestingly, one of the biggest motivators for Fran, Brian, Tony, and Sally was the element of learning something new. Fran in particular spoke about how the consequences of new learning:

"I've enjoyed everything I've done because it is an achievement."

When asked what it was that gave her the sense of achievement, she stated:

"That I've never done it before, and me sister will say, "Give yourself a pat on the back!" And I get really chuffed and excited……But it's an achievement because I'm learning……. I've got a lack of confidence so when I do something I feel thrilled to bits."

The new learning gives Fran a sense of control over her dementia – she spoke to me after one of the interviews about how she was hoping to perform better on her forthcoming memory test to prove to herself that she was still functioning well. The new learning is an important consequence for Fran to prove that she is still able to learn. Fran experiences many positive consequences from new learning: increased confidence and self-esteem, achievement and accomplishment, a sense of pride, positive feedback from others, challenging dementia. All of these consequences increase the value of the activity and therefore increase the chances that Fran will participate in them, thus further supporting the movement of value to the occupation itself.

Tony also spoke about new learning as a motivational factor in occupational engagement. In particular, he spoke about the positive consequences gained from the cooking groups at the centre. He stated that he felt he was being introduced to the *“secrets of cooking”.* He talked about how he cooked at home, but that the centre was allowing him to learn new techniques and be more involved with complex recipes. He also spoke about participating in a group where he was making a papier mache pig: making tangible items which could be used at home made him feel *“useful”.*

However, the participants also spoke of times where they were not motivated to participate in occupations. Brian did not feel motivated to participate wholly in the cooking groups, and was observed to find these interesting or indifferent occupations. When asked about this, Brian’s reasons for low motivation for this was interesting, clearly not wanting to be included in this occupation at home:

“They’re alright, but I don’t tell me wife about how much I’ve been doing. I took her a bun home last week which I’d made, and…. cos if I tell her too much she’ll have me doing too much!! [laughed] I can still be canny!”

Fran also struggled with poor motivation at times. Although this was mostly linked to her mood and energy levels, she spoke explicitly about an occasion where she was invited out with a friend:

“Pauline rang me on the Monday just before her birthday on the 19th and said, “I’m off today Fran, do you want to go and do something?” I couldn’t be bothered having a shower and getting ready.”

This lack of motivation prevented Fran from participating in self-care occupations which would then have led to a social event that she previously discussed, stating that she had lost a lot of friends since her dementia diagnosis. This is also a good example of how participation in one occupation leads to another, and how poor motivation for one prevents the participation in another.

Tony also spoke directly about poor motivation and the impact on his participation in occupations:

"Tony: Nowadays, after me stroke, I've got lazy, and I don't fancy doing things. But I realise that and I'm beginning to do things. When I had me stroke, I used to sit in the chair and I didn't feel like doing….no, I felt alright, but I'd no energy…. doctors reckoned I was depressed. Now whether I was, I don't know. Anyway, he gave me pills and…er…I suppose they've uplifted me……… I'm pretty…pretty er…..I'm pretty loose at what I do, you know? I'm trying to think of the word for being loosened up….
Interviewer: So, are you a bit more motivated to do it?
Motivated. That's the word."

This demonstrates the complexities of Tony's poor motivation: prior to his cerebro-vascular accident he was an independent, active gentleman, and following this he found that he was affected physically and mentally. He describes how the after effect left him feeling depressed, which in turn greatly reduced his motivation for participating in occupations. Once this was recognised and treated with medication, Tony's mood lifted and his motivation for participating in occupations increased. Understanding the cause of Tony's poor motivation for participation in occupations allows his to receive the appropriate interventions (in this case medication) so that he can begin to participate and be engaged in occupations again to achieve a greater sense of wellbeing (which in turn will help to lift his mood further).

The identification of motivation as a factor which influences participation is important for the participants of this research. At first glance (and during observations), it may appear that they did not find value in the occupation or that the consequences of participating were negative. But by examining the motivational factors of the individuals as discussed in the interviews, a deeper understanding is gained about why they were reluctant to participate, or the intensity was less than expected. It was therefore felt that this should be included in any future developments of a framework to encourage therapists to investigate this further so that appropriate support or intervention can be provided to enable participation (e.g., with Fran and Tony), or so that different occupations can be introduced (e.g., Brian).

9.1.iii Physical factors

Physical health was a major component for all of the participants. All had health complications that challenged their ability to participate in occupations and to experience the most positive consequences. The major factors in this for the participants of the research were:

- Pain
- Mobility
- Energy levels
- Physical aids

9.1.iii.a Pain

For Fran in particular, pain was a major influencing factor over whether she participated in occupations or not. She spoke about her pain during the interviews and the impact it had on her ability to engage in occupations. This was both in terms of whether she was able to participate or not, and also the depth of engagement achieved. This was seen within the observations, where Fran would begin an occupation and be absorbed by it. As her pain levels increased during the occupation, it would become less absorbing and more interesting.

Sally also spoke about pain being an influencing factor in her participation in occupations. She experiences pain in her legs which prevents her from walking far. This affects her ability to visit her son and go shopping in the local town, thus preventing her from participating in several occupations:

"I used to do quite a bit. I'd go on the bus and go shopping, but I haven't been able to go on the bus for quite a while now with me leg. And me son lives in -------- well, I haven't been able to go and see him, you know, cos I walk too slow."

9.1.iii.b Limited Mobility

For Fran, Brian, Sally and Tony, limited mobility was a significant factor in participation in occupations. As discussed previously, Fran experiences a lot of pain and with this comes limited mobility which prevents her from participating in some activities and limits the depth of engagement.

Similarly, Brian has limited mobility and a history of falls, which prevents him from participating in some occupations and is very limiting for him.

Sally described how her poor mobility prevents her from going shopping, carrying out household chores, including cooking meals, and prevents her from visiting her son. This clearly has a huge impact on her ability to participate in valued occupations.

Tony also described how his poor mobility following his cerebrovascular accident has significantly affected his ability to participate in occupations. He described how he has difficulty participating in occupations such as gardening and DIY because of his poor mobility and history of falls.

9.1.iii.c Energy Levels

Both Fran and Sally spoke at length about their energy levels and the impact of this on participation in occupations. Fran spoke about how the days at the centre were exhausting for her and how she would go home and fall asleep. Interestingly, Fran viewed the tiredness from attending the centre as a positive consequence, even though it prevented her from participating in other occupations. Whilst this could be viewed as a negative consequence, Fran viewed it more positively because she valued attending the centre. Fran spoke within her interviews about how she had improved over the time she had been attending the centre, and therefore felt benefit in other ways from attending. Although Fran described some negative consequences from individual activities at the centre, the overall positive consequences she experienced placed a higher value on attending, meaning overall consequences were positive.

Sally became visibly tired during the interviews. She explained how she felt very tired most of the time and this impacted on her ability to participate in occupations that she would ordinarily participate in. This was more noticeable during Sally's second interview: she had a hospital admission in-between interviews and this left her feeling more tired. When observed within the occupations at the centre, Sally was noticeably tired and would often close her eyes and fall asleep whilst in the middle of an activity. This directly demonstrates the in-the-moment feedback from consequences and how they can affect participation and intensity during an occupation.

9.1.iii.d Physical Aids

All of the participants spoke about their use of physical aids in relation to participation in occupation, and how these aids supported them in participation and, in some cases, prevented participation if they were without them.

Fran and Sally spoke about the use of glasses (spectacles). Both talked about how they had forgotten to take these to the centre on occasions and as a result had been unable to participate in the occupations as they could not see properly. Sally also spoke about her cataracts, and how these prevented her from participating in a valued occupation:

"I've had me eyes done. So I was annoyed with that because I couldn't see, and I like to read in bed. And with not being able to see, that used to really get me going. Anyway…. I've had them both done now."

Similarly, Fran, Brian, Ethel, and Sally all used walking aids. Whilst this was a difficult adaptation to make because of the challenge to identity (as discussed by Sally previously), these aids enabled the individuals to maintain a degree of independence and to continue participating in occupations.

Brian also spoke about adaptations and aids at home and also continence aids which enabled him to continue participating in occupations. Without these, he would be much more limited to what he was able to do.

During observations at the centre and also during the interviews, it was clear that hearing aids are also an important factor to consider in the participation of occupations. Brian, Fran, and Peter all wore hearing aids, and even with these their hearing was reduced and they had difficulty hearing what was said. In the group activities it was observed that if they could not hear the instructions or discussions, their participation and engagement was limited.

Whilst physicality is a key consideration in their work with individuals, the experiences of the participants highlight the importance of ensuring that the correct aids are provided and used. Not only is this key to ensuring that participation in occupations can continue, but new research suggests that the correct use of aids such as glasses and hearing aids helps to improve quality of life, reduce dependence, and increase functional ability (Leroi et al., 2020), thus enabling the participation in valued occupations.

9.1.iv Cognitive Function

Brian, Tony, and Fran were the only participants who explicitly spoke about their cognitive function during the interviews. Brian was acutely aware of his dementia diagnosis and explained during the assessments that he was still able to function in spite of this. However, his cognitive function was affecting his ability to participate in some occupations.

Fran stated that she liked participating in new occupations which allowed her to learn. She implied that this was a challenge to her dementia diagnosis and proved that she was still capable of new learning. During the interviews Fran spoke of how her cognitive impairment had meant that she was now unable to drive. The loss of this occupation was far reaching for Fran: she enjoyed driving her sporty car and experienced a lot of pleasure from this. In addition, this allowed her the independence to go where she liked, when she liked. Since she stopped driving, she was unable to go shopping independently to buy the items that were important to her for her appearance, or go to the hairdressers when she wanted. She spoke about how this meant she was reliant on others, which affected her confidence and mood. This also had an impact on her relationship with her husband.

Peter was unable to describe his experiences of impaired cognition on his participation in occupation, however the extent of this was observed in the activities at the centre. Peter had difficulty participating in some occupations because of his cognitive impairment. Staff at the centre supported him in order for him to participate in the occupations and they chose which sessions he attended to allow him to experience positive consequences.

Ethel, Sally and Fran all acknowledged that there were some occupations at the centre that they were experiencing difficulty with because of cognitive impairment. In particular, they all spoke about knitting. They had all been proficient at knitting previously, and all found it a valued occupation. However, when they were encouraged to participate in knitting at the centre they all found it a very difficult task. It remained valued but eventually they all stopped participating because the occupation itself was too difficult cognitively for them.

Tony explained during the interviews how his cerebrovascular accident resulted in cognitive impairment which prevented him from participating in his most valued occupation: radio broadcasting. Tony found this very frustrating and worked extremely hard to re-learn the code. He spoke in the interviews how he had managed to overcome his difficulty and at the time of the interviews was once again participating in the broadcasting and communicating with others internationally.

This may seem an obvious factor for consideration in individuals with dementia, after all the very nature of dementia affects cognition. However, it requires placing within the framework as an explicit consideration. This helps to retain the focus and importance of cognitive impairment on participation in occupation, and also ensures that it remains a consideration should this be applied to individuals without dementia. Assessment and acknowledgement of cognitive impairment in individuals helps therapists to grade and adapt occupations so that they remain accessible to individuals. This is especially important for successful participation in valued and new occupations which support self-identity and wellbeing.

9.1.v Resilience

Resilience is an element of self that was demonstrated by many of the participants during the interviews. Resilience is defined as:

> *“the ability of people or things to recover quickly after something unpleasant, such as shock, injury, etc.”*
>
> (Oxford English Dictionary, 2021)

In the case of the participants of this research, the resilience was shown against their physical and cognitive changes. Many participants found that they were no longer able to participate in valued occupations, which they found frustrating. However, rather than simply accept this fate, they continued to try and overcome these difficulties and find new ways of doing things. This was most evident in Brian who, at the end of one interview, stated:

"I may have this dementia, so they say anyway, but I still have a brain, and I can still think, and I can still work things out."

Here, Brian is stating that his dementia does not define him and does not mean that he has become an incapable person, again linking back to person centred dementia care proposed by Tom Kitwood (1997), which suggests that we should continue to focus on the person and not the illness. At another point in the interviews, Brian describes how he uses this self-belief to overcome difficulties he experiences when completing crosswords, a valued occupation. He stated that:

"[the crosswords] keep your mind going. I mean like, I've got dementia, but it upsets me if I can't spell something. I try me [sic] best to spell the words but it upsets me when…. if I can't spell something. I try me best to spell the words, but if I'm not sure I look in me dictionary and see what the meaning of the words is. But errr……even though I can't get about and can't move about, I try in a way not to be idle."

Brian works hard to overcome any difficulties he faces, and does not let his diagnosis define who he is or prevent him from participating in occupations – he finds a way around it.

For some of the participants, family members placed restrictions on them as a result of concerns about welfare, usually around risks of harm physically. This was particularly the case for Tony, who stated that his wife "forbids" him from participating in certain occupations. For Tony, this was mostly around mowing the lawn and climbing ladders. He spoke about how he still continues to participate in these occupations, but waits until his wife is not home!

"I mowed the lawn last week on day……She goes on a Tuesday for about five hours. She just helps out, but she's gone then, so I get the mower out and mowed the 2 lawns."

Tony also showed great resilience with regard to his radio broadcasting. Following his cerebrovascular accident, he forgot all of the coding he used to communicate with others over the radio. Since then, he worked hard to re-learn the code and at the time of the interviews was back broadcasting again.

During Fran's interviews she spoke about difficulties between her and her husband, which meant that she did not always receive the support she needed. During one interview, she spoke about how she had asked him to bring her a cup of tea and a slice of cake, but he did not do this:

"Anyway, he didn't bring the cake cos he was annoyed at me. So I went downstairs and I got my own. I thought, 'I don't care, I'll show you!'"

She also spoke about how her husband had hidden some Christmas cake slices on top of the kitchen units out of her reach and how she planned to get them:

"Yeah, but I will reach them, because I will get one of my utensils out of my thingy, and I'll flick 'em off!"

During her interviews, Fran spoke a lot about her love for clothes and how frustrating it was to not be able to go to the shops to buy them. However, in spite of this, she had found a way of still obtaining clothes by shopping online, although this also caused some difficulties because she was spending a lot of money on her husband's card.

Ethel summed up the premise for her own resilience:

"I think you're entitled to have a bit of your own way with some things when you've lived as long as I have."

Although some might perceive this as her being difficult, she is expressing the importance of her own individuality and not being forced to do things that please other people all the time. This is a really important factor for people working with people with dementia to consider: the wishes of the person are paramount, and they should not be ignored at the detriment of that individual's own preferences and choices, again linking to the importance of person-centred dementia care, considering the individual and not the illness (Kitwood, 1997).

Although the participants described several instances where they demonstrated their resilience and efforts to overcome their difficulties, the crux of their drive to persist in participation in occupations was explained by Brian, Ethel, and Sally. Brian (as demonstrated above) wished not to become idle. Ethel spoke about her desire to remain engaged in occupations:

I wouldn't like to not be doing something. I'd have to be doing something."

And Sally spoke about 'doing being life'.

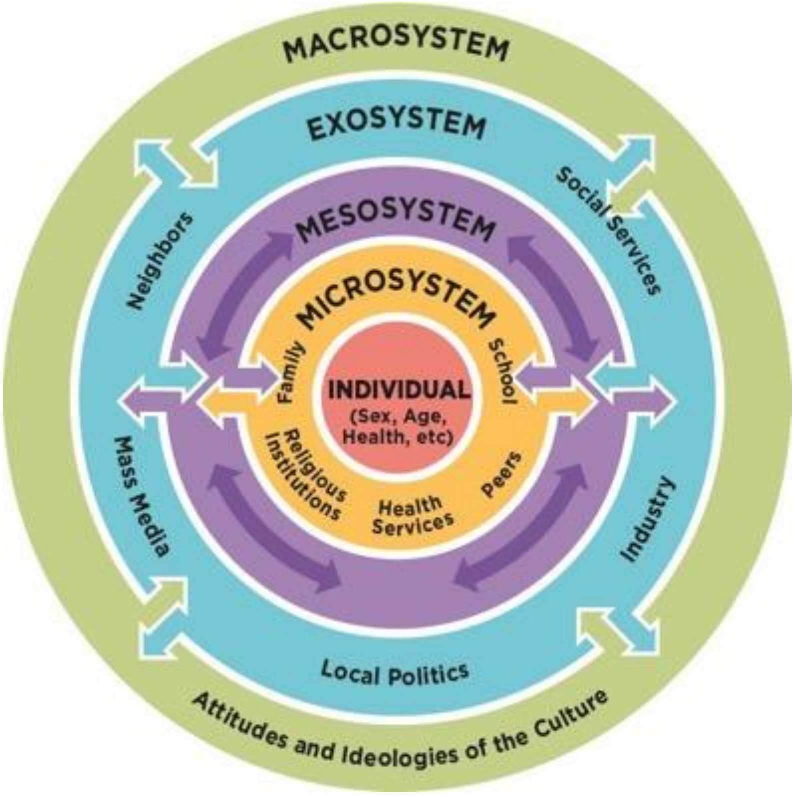
Not only do these statements demonstrate the absolute importance of occupational engagement for these individuals, but they also provide an insight into the motivation of the participants to remain occupied, and hence the resilience they show when factors such as physical disability and cognitive impairment threaten this.

9.2 Social Ecosystem

The term 'social ecosystem' is based in Ecological Systems Theory was first introduced by Bronfenbrenner (1979). This theory examines an individual's relationships within communities and the wider society. It was felt that this approach to the participants of this research would allow examination of the various relationships that they hold and to examine their influences on the person and the influence this has on their participation in occupations.

Figure 9 below demonstrates the different ecosystems identified by Bronfenbrenner which exist around a person – each one sitting within the next to demonstrate the effects of each on the other.

Figure 10: Bronfenbrenner's framework (1979)



For the participants of this study, the microsystem was the most influential on the participation in and consequences of occupations. However, some elements of the exosystem were also apparent, e.g., Social Services, who may have been responsible for enabling the individuals to attend the centre, and also neighbours: Ethel in particular was influenced by neighbours who facilitated her in attending appointments and shopping. This framework would also apply to individuals from other demographics e.g., younger adults who may be influenced by work or social media, and allows for influences such as mass media e.g., the news and politics.

The work of Bronfenbrenner is useful for thinking through the dynamic relationship between the individual and their social environment that this research identified. This will be different for every individual and indeed is reliant on the perceptions of that individual around their social support. This particular model is useful because it places the person at the centre of all social interactions and considers the links between the different social influences on a person. Ordinarily, only the immediate social interactions might be considered (e.g., with family or peers), but Bronfenbrenner's model also considers the wider influences of politics, media, health and social services and the wider culture that a person lives within. When considering an individual, these social influences can create positive or negative effects which may then have an influence on the value of an occupation to the individual and whether they choose to participate in it. Within the context of the proposed framework, the work of Bronfenbrenner can help us to consider the wider social influences of an individual instead of focussing only on the immediate social network.

The next proposed area of influence over participation is the social factors which surround the person with dementia. There are several factors which were found to influence participation in occupation for the participants of this study in relation to social factors:

- Peers
- Family
- Support systems

These are discussed below along with further complexities within these.

9.2.i Peers

The influence of peers was raised several times by some of the participants. This was in relation to both friends and attendees at the centre, but mainly around comparisons and friendships formed at the day centre.

Fran explained that she had a lot of friends prior to her dementia diagnosis, but that she had not heard from them in a while.

In relation to people at the centre, Fran had developed some close friendships with other attendees. She enjoyed talking to her friends at the centre and was always concerned over their welfare. She was particularly close to one lady at the centre and was observed to want to participate in the same occupations as her, although staff at the centre limited this to enable her to mix with others. Fran was also acutely aware of the deterioration of her peers at the centre, and this affected her mood at times. She spoke in depth about Peter: shortly before the study began, he had been unwell and had attended the centre wearing different clothing to his normal attire.

Fran also spoke about her concern over another lady at the centre, and this caused her to be preoccupied during her time at the centre. This affected her participation in the planned sessions as she felt that she had to speak to staff about her concerns. She also stated that she continued being concerned about the lady when she had returned home from the centre, affecting her participation in occupations at home.

Sally spoke about other attendees at the centre, stating that she had swapped days because she did not want to continue on days where predominantly men attended. She found these days particularly difficult and asked to switch to another day where the gender mix was more equal. Sally felt that the days with more men attending affected her participation and made her more tired.

Following a shopping trip, Ethel made observations about her peers at the centre, stating that she felt that they were different to her. This discussion followed being asked what she had enjoyed about the shopping trip:

“I enjoyed being with…. being normal. Cos you’re not always. Sometimes there are people that are not quite……you know, they’re not right……I don’t feel that I am different, but I sometimes see people that feel…look different…. they

have, sort of a bit of a vacant look about them……you can tell they are not seeing what is there. They're looking but they aren't taking in what there is."

Ethel was referring to the other people at the centre, and it was observed that she did not often speak with her peers, choosing instead to seek out staff at the centre. This quote implies that she does not relate to the other attendees at the centre, seeing them as different. Although not explicitly stated in the interviews, it could be understood that this may be a factor which limits Ethel's participation in occupations at the centre because she does not feel a connection to her peers because they are different.

The relationship between peers and occupation described by the participants makes this a key theme with any considerations of occupation, especially those attending a day centre. Participants described how positive contact with peers encourages participation in occupations and can make the consequences more positive. However, if the individual considers that their contact with their peers is less positive (as for Sally and Ethel), participation in occupations becomes less likely and the consequences from this are more negative. This places importance on the consideration of the effect of peers in settings such as a day centre, where individuals are put together with others whom they would otherwise choose not to socialise. The implications of poor peer relationships can influence the success of participation in occupations and the consequences that follow.

9.2.ii Family

For all participants, family were important factors in participation in occupation. There were two clear elements to this: enabling and inhibiting. These two factors often determined whether a person participation in occupations or whether they avoided them.

9.2.ii.a Enabling

For all participants there were some family members who encouraged participation in occupations. Family members were crucial to participation in many valued occupations and facilitation varied between encouragement, shared participation, and facilitating the occupation.

For Fran, her sister and daughter were encouraging of her occupations at the centre and were always pleased to see the items that she had made. Her daughter also asked if she could take the items home to keep, which created a sense of achievement and pride for Fran. The comments made to Fran about her creations encouraged her to participate in further occupations at the centre.

Brian's wife shared several valued occupations with him. He stated that she had begun art classes with him, and also that they sang together in the singing for the brain group. This was very important to Brian, and he was extremely proud of her achievements in these occupations. He stated that he enjoyed sharing these occupations with her, and they encouraged him to continue participating in these valued occupations. Brian also spoke about his wife and how supportive she was in helping him to lead as independent a life as possible:

"There's a lot I have to rely on my wife for. But I do try and do things for myself, and she appreciates that I try to do it because a lot of other people let themselves go don't they? ……. That's one good thing about my wife. I can talk to her about things, and she understands. And just like things like having a bath and that sort of thing. She knows what my limitations are."

Peter's wife was highly involved in facilitating his participation in occupations, particularly those relating to his religious beliefs. She also facilitated his participation in colouring and framing his work by ensuring that he had the correct tools for doing this and taking him to the charity shops to buy the frames.

Tony's family were also facilitators in him participating in occupations. Tony expressed how he enjoyed bird watching and fishing, and he was unable to participate in these occupations unless someone took him as he could no longer drive. His family were an essential factor in him being able to participate in some valued occupations.

The result of the enabling relationships with family was that individuals were able to continue participating in valued occupations and achieving positive consequences. The greater impact of this being an increased sense of wellbeing and ultimately the self-identity of the individual being supported.

9.2.ii.b Inhibiting

During her interviews, Fran spoke a lot about her relationship with her husband. It was Fran's perception that he did not respond to her needs and was dismissive of her. Fran spoke about this was inhibiting as she felt her husband was not supportive of her and prevented her from participating in some valued occupations.

Sally spoke about her daughters during her interviews. It was clear that her daughters were supportive of her and were trying to protect her from harm, however their input was very inhibiting for Sally. Her daughters prevented her from participating in many daily occupations such as housework, cooking, shopping, in order to keep her safe and minimise the risk of falls.

Similarly, Tony's wife tried to keep him safe by preventing him from participating in several occupations that she felt would result in injury. Tony had been prevented from gardening and DIY, and he was frustrated by this. In fact, Tony spoke about how he would wait until his wife had gone out and would participate in the prohibited occupations whilst she was not there!

Inhibiting relationships with family were described by participants as having a negative impact on participation in occupations. If we consider the comments raised about the importance of doing and not being lazy or idle raised by the participants, then we can clearly see that the impact of being prevented from participating in daily occupations is potentially vast. In particular, Sally spoke about her daughters (albeit well meaningfully) had prevented her from participating in many daily occupations. This significantly reduces the possibility for participation, increases the amount of time spent unoccupied and increases the chances for the individual to feel lazy or idle. This then becomes an important consideration when working with people with dementia. It may be that relatives need to be educated on the importance of occupational engagement and/or positive risk taking, or further investigation into alternative valued occupations may be needed to increase a sense of wellbeing (and indeed purpose).

9.2.iii Support Systems

The many systems identified by Bronfenbrenner (1979) have been grouped together in this section to avoid further complication. The support systems which surrounded the participants of this study were essential to their participation in occupations. Whilst peers and family are a part of this, there was a wider support system which enabled the participants to access valued or important occupations. The most obvious of these is the day centre itself. The staff at the centre facilitated access to a variety of occupations which are appropriate for their current level of cognitive and physical function. Sally in particular valued the support from staff at the centre with the activities, and it made her more successful in achieving positive consequences.

Sally also spoke about her conversations with other people, such as a stranger in a shop who had a hairstyle she liked, and how she wished to speak with a sales assistant on a beauty counter who could advise her on the correct make-up to wear. These conversations would provide positive reinforcement for Fran and encourage her to participate in occupations related to these topics e.g., going to the hairdressers for a similar cut and colour, putting make-up on which helps to support her self-identity.

Ethel spoke about her neighbours during the interviews and how they had supported her to attend appointments at the hospital before. She also described her experience with a taxi driver who had been called to take her to an appointment. This was not a positive experience and she felt that he had abandoned her and left her to find her own way around a large and busy hospital, which resulted in many negative consequences at that time (increased anxiety, worry, feeling a fool in front of her consultant) and in the longer term has affected her confidence about attending future appointments. Ethel also spoke about a neighbour who had taken her shopping to allow Ethel to buy Christmas gifts for her family. Without this, Ethel would not have been able to access the shops and would not have been able to offer gifts to her family.

For Brian, the additional support systems included the volunteers at the Singing for the Brain group he attended and the facilitator at the art group. These individuals helped him to participate in the occupations by ensuring that it was accessible cognitively and physically.

Peter remained an avid church attendee and volunteer, and the members of the congregation supported him in continuing his volunteer work at the church and achieving positive consequences from this. This was a very important and valued occupation for Peter, and their support was essential to his wellbeing.

Tony spoke about his attendance at an exercise group. The facilitator of this group was key to his participation and not only did this ensure positive consequences from each session, but it also contributed to his physical recovery from his cerebro-vascular accident, which allowed him to participate in other occupations away from the group.

As with the importance of peers and family support, the influence of wider support systems was crucial for the participation in some valued occupations for the participants. This highlights the need for this to be considered when examining participation and engagement in occupations, as individuals may need help in accessing the most appropriate support systems to enable them to continue participating in valued occupations.

9.3 Environmental Influences

There are many complex environmental factors which affect people with dementia, and these have been previously researched e.g., lighting, colour, noise, visual cues, building design. However, several participants commented on environmental issues which affected their participation in occupations. The two main issues which arose were around the physical environment and access.

9.3.i Physical Environment

The physical environment was significant for many of the participants, especially with regard to participation in occupations. Fran spoke about her visits to the local supermarket and how her shopping was disrupted when the staff changed the products around on the aisles. When the environment was changed, she was not able to remember to buy all of the items she needed, which affected the consequences of the shopping trip. Ethel also spoke about supermarkets: she stated that she did not like the environment in one of her local supermarkets and as such had a negative view of the store and what they sold, believing it to be lower quality. As a consequence, she avoided shopping there, but when the centre took her for a group visit to the supermarket she disliked, her engagement was different. Ethel also spoke about her experiences at a local hospital where she described a recent incident where she was dropped off by taxi in the grounds of a hospital and had to find her own way to the department. Ethel was disorientated and found this really distressing, stating that she was *“petrified”.* This was a negative consequence for her and affected the appointment which followed and her future appointments at the hospital as she dies not wish to experience the same again.

Brian also spoke about the environment in relation to participation in occupations. He stated that he would no longer be able to participate in singing on stage without adaptation of the environment to allow him to physically access the stage and remain on stage.

These examples demonstrate how the environment can prevent participation in occupations and also how the consequences of poor management of the environmental challenges affects future participation in the same or similar occupations.

9.3.ii Access

Fran, Sally, Ethel, Brian, and Tony all spoke about the impact of access on participation in valued occupations. Some of this was around driving: without access to a car, the participants were reliant on others and could no longer access the occupations they wanted when they wanted. This was particularly the case for Fran and Tony, who both spoke about occupations they were no longer able to participate in because they could not physically access them, although the cause for the inaccessibility was based around cognitive impairment: both had to surrender their driving licences following a diagnosis of dementia.

Brian spoke about his inability to access the theatres which would allow him to perform on stage, and Sally spoke about her difficulties accessing the bus services which would take her to visit her son. These were a result of poor mobility and demonstrate how physical disability can impact on an individual’s ability to participate in valued occupations.

Without direct access to the place that the valued occupation is occurring, and without support to access these places, some occupations are out of bounds for individuals who would otherwise participate in them.

9.4 Summary

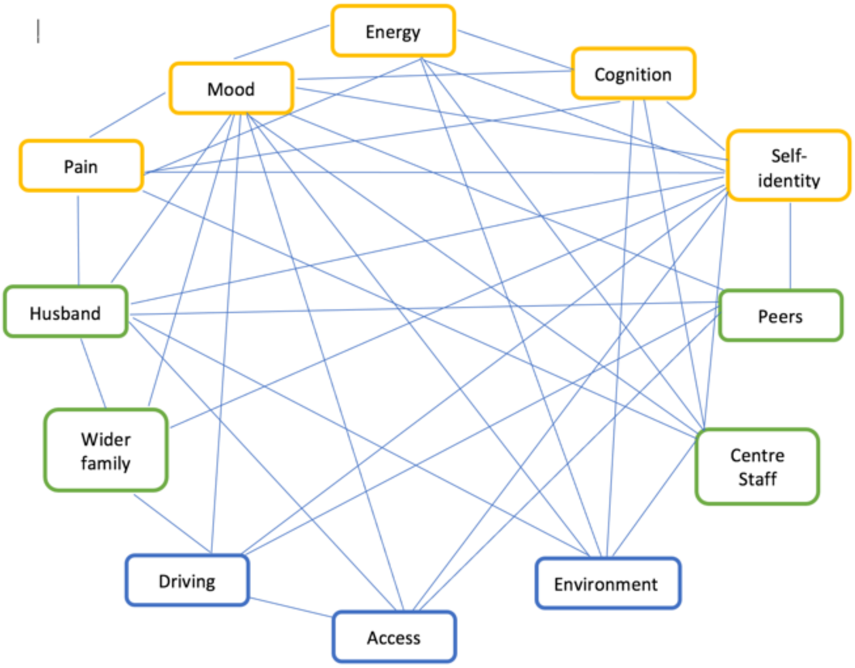
This chapter has explored the complex factors that were identified in the analysis of the data from interviews and observations. Whilst the original framework explored some of these elements, it did not explicitly consider the complex interplay of these and the impact they have on the participation and engagement in occupations. Throughout the analysis, it became clear that these factors were not only important to the participants (being their lived experience), but also that they should be included in the formulation of a new framework. This would help therapists to understand and explore the factors which impact on the participation in occupations so that they may help to overcome any challenges and support the participation in valued occupations so that self-identity can be maintained, and wellbeing achieved.

10. Complexities Explored

So far, the complex internal and external factors that were relevant to the participants have been explored. However they have been explored in a linear fashion, with no further cosideration around their actual complexities. Each of the factors explored has a direct influence on at least one other factor, and their relationships are what makes these elements of participation complex. For example, low mood can affect motivation and cognition, which in turn can affect self identity and energy levels. Pain can affect mood, energy levels and motivation. Relationships with others can have a positive or negative effect on mood and, as stated by Tom Kitwood in his Person Centred Approach to dementia care, cognition (Kitwood, 1997). The intricate relationships between the different factors that affect participation in occupation are what creates the complexities, and these will differ between individuals and will be fluid for each individual according to time and place.

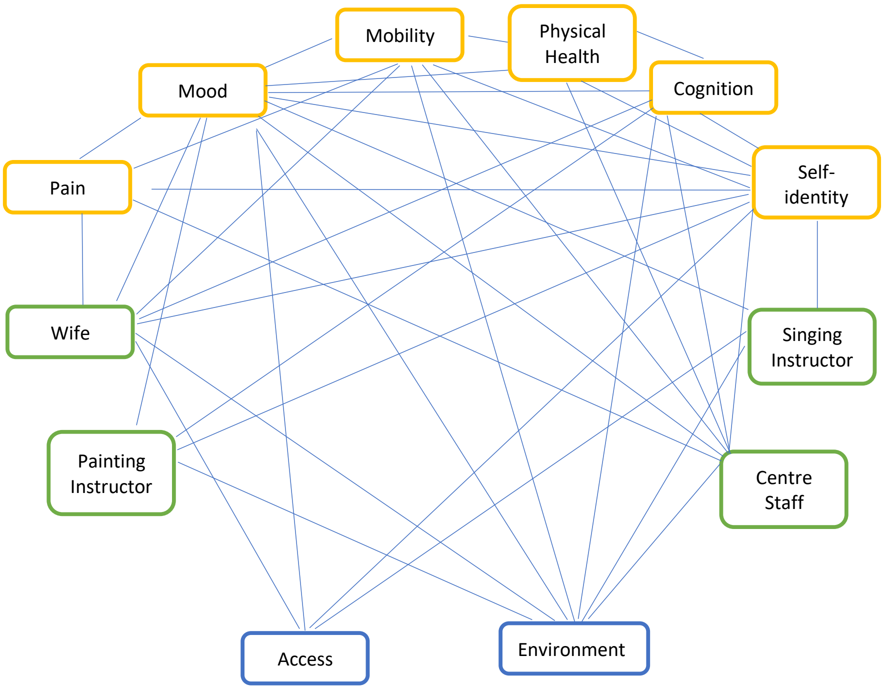
In order to attempt to demonstrate the complex relationships between the factors, Figures 11-16 demonstrate some of the complex interactions that occurred for the participants of this research. The colours of the boxes relate to Figure 9: Self (Yellow), Social Ecosystem (Green), Environment (Blue).

Figure 11: Complex Internal and External Factors for Fran



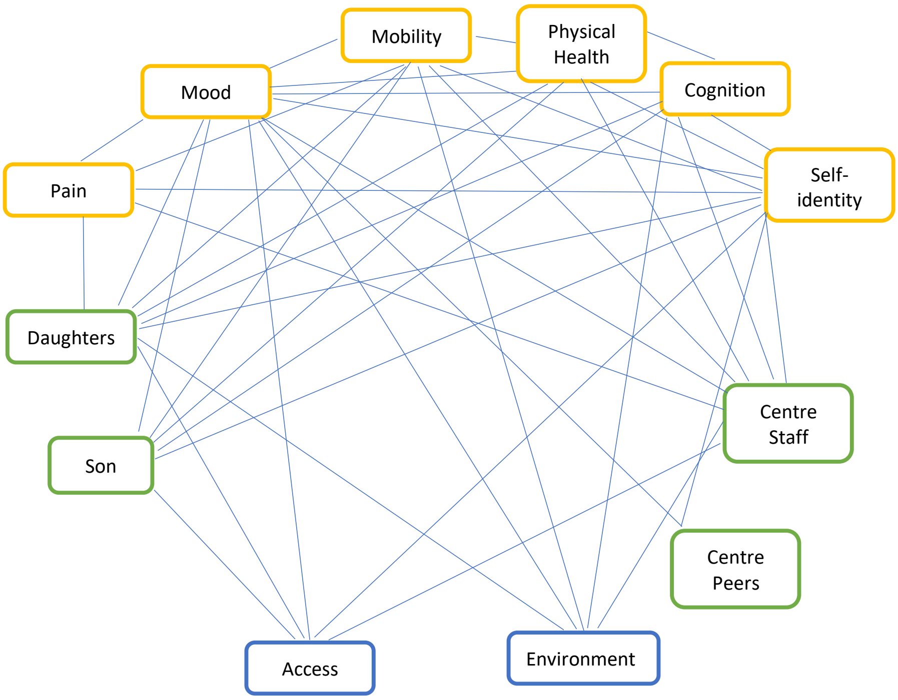
This diagram shows for Fran that the internal and external factors were almost equally distributed. However, on closer inspection, we can see that self-identity and mood were particularly important factors, and that her social ecosystem, self and environment both affected and were affected by these elements. Fran identified the centre staff as being particularly influential in her social ecosystem, and her relationship with her husband was a key factor with regard to self.

Figure 12: Complex Internal and External Factors for Brian



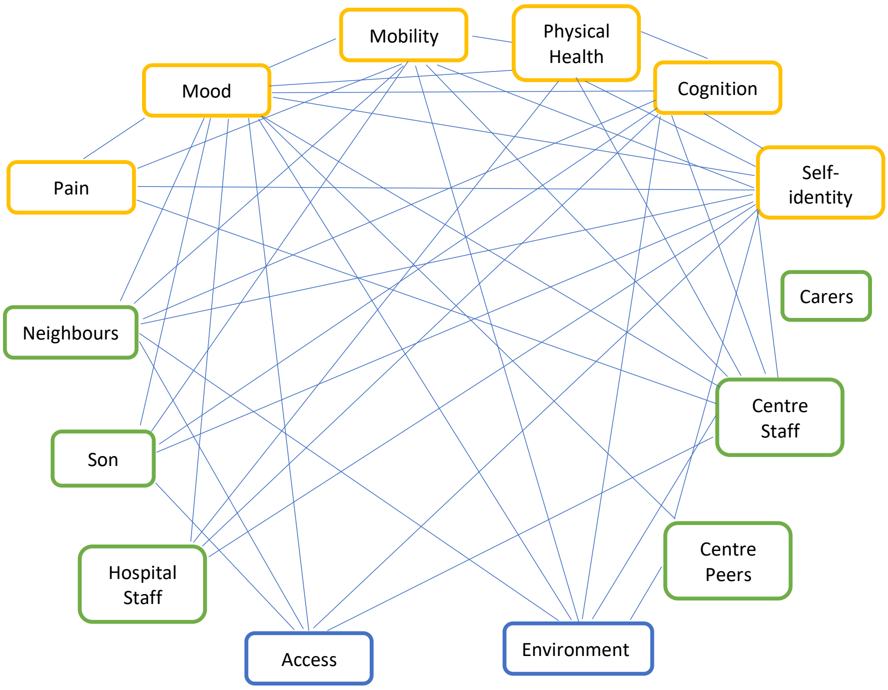
When considering the complex internal and external factors for Brian, we can see that mood, self-identity and physical factors are particularly significant for him. In addition, the influence of others such as his wife, his painting instructor and staff at the centre are key, as is the environment and access. It is clear to see from this diagram that the factors influencing Brian are concentrated more around self and social ecosystem.

Figure 13: Complex Internal and External Factors for Sally



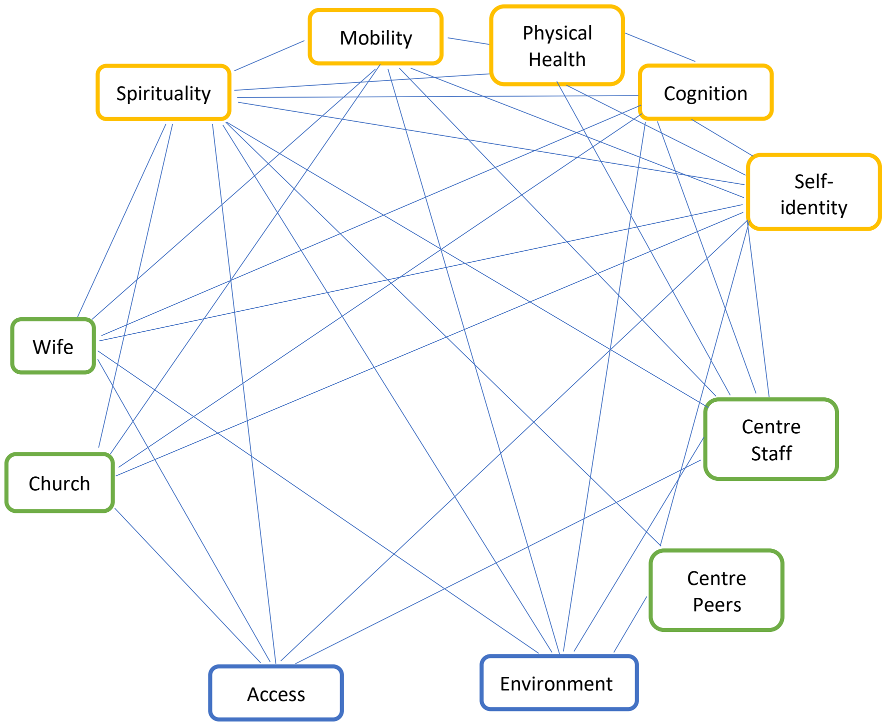
Sally's complex internal and external factors are similar to Brian in that they are more concentrated around self and social ecosystem. In particular, mood, self-identity and physical health are important, as are the influences of her children and centre staff. Interestingly, Sally did not have any other influences in her social ecosystem, whereas other participants did have a wider range of factors in this area.

Figure 14: Complex Internal and External Factors for Ethel



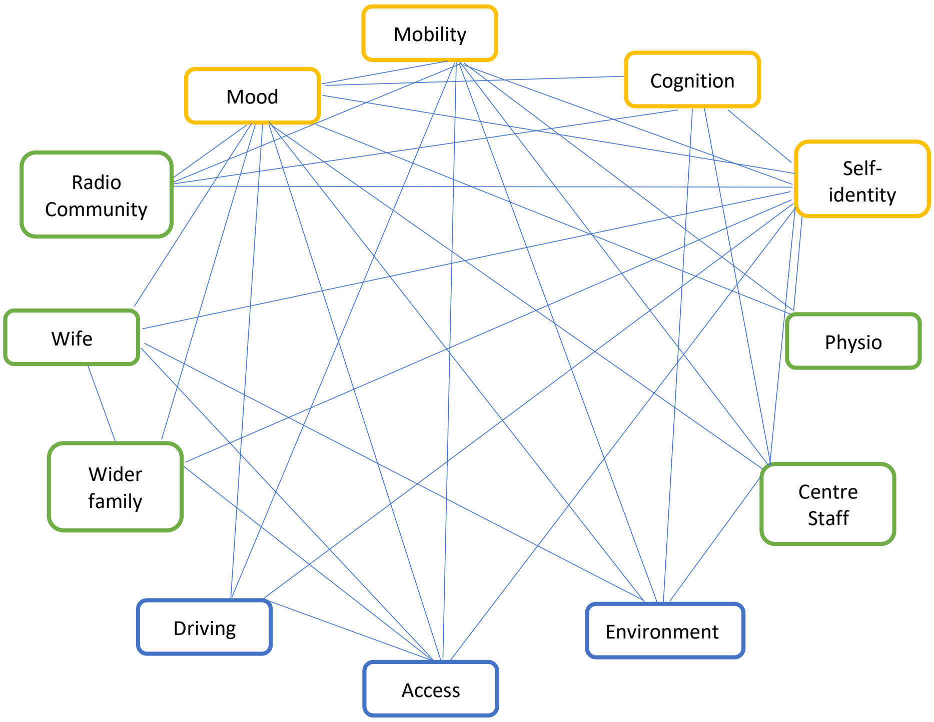
As shown above, Ethel has a much more extensive system of internal and external factors. As with previous participants, self-identity, mood and physical health were particularly significant, however she has a more complex social ecosystem which all influence self. Ethel identified others outside of her own family as being particularly influential on self, and this included hospital staff who were not well known to her which indicates the significance of interactions with others in the outer circles of the social ecosystem.

Figure 15: Complex Internal and External Factors for Peter



Peter’s internal and external factors are fewer than the other participants. This is in part a result of the data obtained, but also demonstrates the important elements of his own life. In this instance, spirituality and self-identity were particularly significant factors. These were influenced by his wife, the church and centre staff in particular. Interestingly, Peter did not identify his physical health as a more significant factor, placing more of an importance on other elements of self.

Figure 16: Complex Internal and External Factors for Tony



The internal and external factors for Tony are well distributed. As with Fran, driving was an important factor environmentally, and affected his ability to access occupations. Interestingly, as with the other participants, Tony also highlighted that self-identity and mood were significant factors, and also identified mobility as an important factor for occupation. Tony also identified that access was particularly important and that this was influenced by his social ecosystem and had an effect on self.

There are many complex interactions between the various factors which is clear to see. The individual factors and the complex associations between them are individual to each participant, however it is clear that the greatest links are around self-identity for all of the participants. This emphasises the need for considering each individual separately, and follows the phenomenological concept that individuals have unique experiences and perspectives which need to be understood. Only then can we begin to offer true person-centred approaches to care which take account of these factors in order to enhance the opportunities to participate in occupations and achieve maximum engagement, enabling a person to live well with dementia (or any health condition).

11. Positive Wellbeing and the Importance of Occupational Engagement

The original framework describes how a balance of occupations with a positive, negative, and neutral value result in a sense of wellbeing in an individual, with the more positive value occupations leading to a greater sense of wellbeing. This remains true for those within the study: engagement in occupations which held a more positive ‘value’ (or as proposed, were more positively intense) created a greater sense of wellbeing in individuals than those which were negative in value (or negatively intense). However, what was apparent in this research was the impact of being unable to participate in valued occupations.

This was notable for several of the participants. Fran became tearful during the interviews when speaking about the occupations she was no longer able to participate in (such as shopping for makeup and driving), and Sally spoke about how she was no longer able to visit her son because her poor mobility meant that she could not travel on the bus. Brian spoke about this in detail in his interviews, stating:

“I’ve always been busy. And that’s the worst, the main thing that upsets me……. I know what needs doing, and I know that if I could stand up alright I could do it. That depresses me.”

He became tearful when talking about the occupations he can no longer participate in, and it was clear that being unable to participate in occupations had a negative impact on his wellbeing. Phenomenologically speaking, the participants defined themselves by their occupations, and in losing the ability to participate in these valued occupations their self-identity was challenged, and this had a significant impact on their wellbeing. Therapeutically this is significant, because people with dementia may lack the cognitive skills to redefine their self-identity and discover new occupations which reflect them individually. This also links with the new learning which was so highly valued by some of the participants: finding new occupations that are valued and provide successful, more positive intensity engagement and positive outcomes is beneficial in supporting self-identity and a sense of wellbeing.

During one of the interviews, Sally made an interesting comment about the value of occupation. We were talking about her attendance at the centre, and she commented that she valued attending because it was *"doing something".* When asked if doing something is important, she replied, *"Well, life is important."* We clarified this a little further and agreed that she believed *doing* is life. This is such a significant statement, and links with occupational therapy theory about the value of occupation and the importance of this in relation to physical, emotional, and mental health: without occupation there is no 'life'.

12. Proposed Changes and Developments to the Occupational Engagement Framework

Having discussed the elements of this research which both supported and challenged the original framework, considerations for changes are now proposed. Whilst the principles behind the original framework were supported, some changes are suggested which would make the framework easier to understand and also which demonstrate more of the complexities of occupational engagement for the participants of this study and make it more applicable to people with dementia. Each element of the proposed framework is discussed in turn to explain how this can be applied to the participants of this research.

12.1 Occupational Engagement: Situational Arguments

In the original framework, Morris (2012) argues that occupational engagement is situated within a value framework and depicts it as one of the values of participation. However, the framework itself is titled the Occupational Engagement Framework. This was perhaps one of the most difficult concepts to understand within the framework: if the framework as a whole is considering occupational engagement, then should ‘engagement’ be considered as more than a value.

After completing this research, I argue that the framework as a whole should consider the occupational engagement of an individual, and that the factors discussed in this thesis are all essential parts of understanding that process for an individual. The original framework states that the *value* can be positive or negative, however I argue that it is the *engagement* which can be positive or negative (or as argued, more positively or negatively intense). Value was discussed in Chapter 8, and it is argued here that the element of value within occupational engagement is related to the occupation itself. This was concluded following the discussions with the participants of this study, as the personal value of the occupation remained the same even if they were unable to participate or if their engagement was more or less positive.

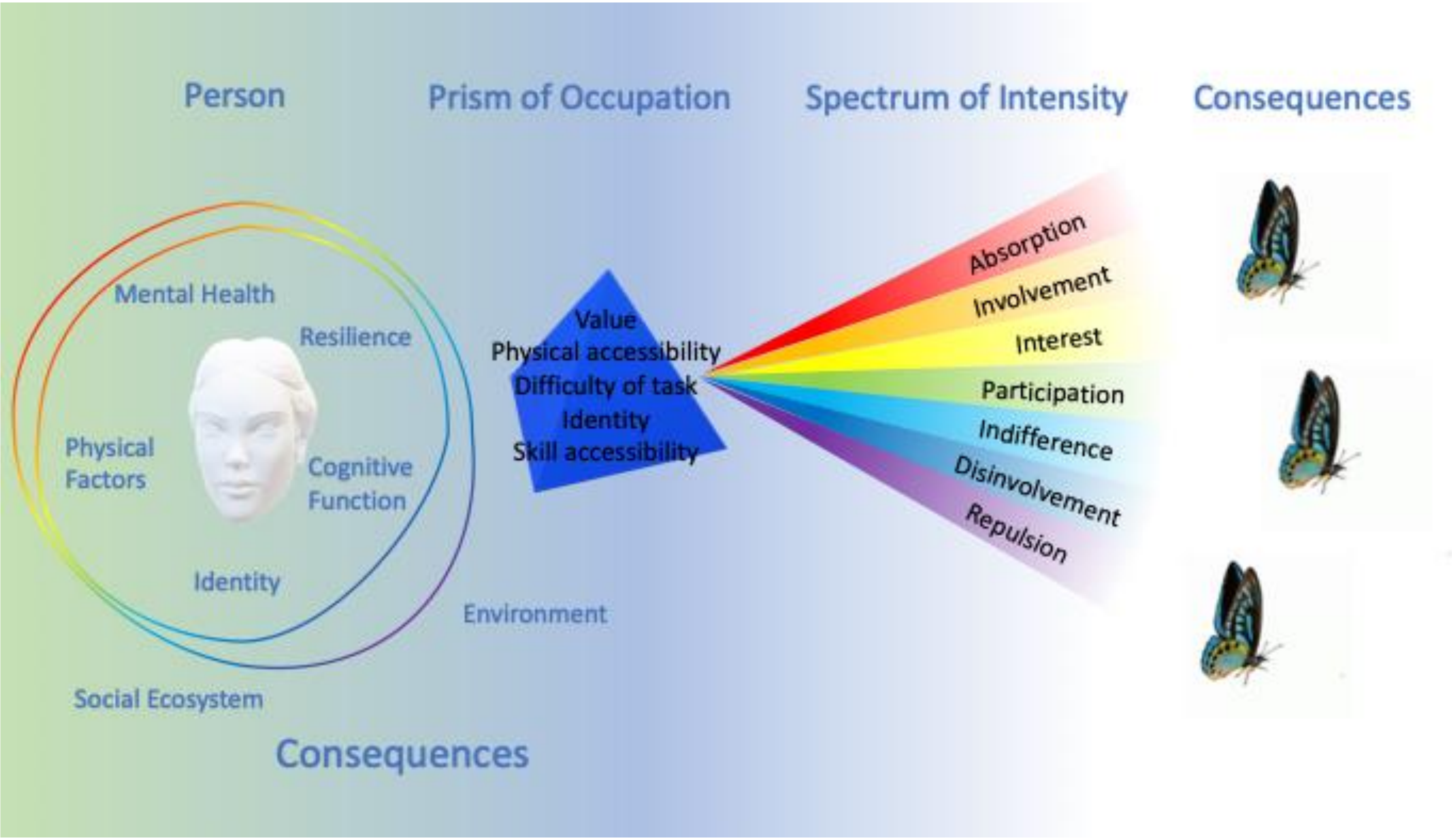
It is also argued here that occupational engagement is itself a spectrum of engagement rather than a value situated within a series of values, as argued by the original framework. It is argued here that the engagement itself is measured in intensity, with absorption being more positively intense than interest, and repulsion being more negatively intense than disinterest. The depiction of this as a spectrum evolving from the prism of occupation creates a sense of fluidity as happens in the process of dispersion. The fluidity between the elements of the spectrum represents the engagement of some of the participants during this research, for whom the intensity changed as the occupation progressed according to feedback received from consequences.

Additionally, the names for two of the measures have been adapted, with engagement changed to involved and disengagement to uninvolved. This is to remove the term ‘engagement’ from within the spectrum to avoid confusion over what is being referred to. The two words are synonyms of one another, and both imply that the person was actively engaged in the occupation but not as much as being absorbed and more so than being interested. These were the only descriptive words changed as it was felt that the others represented the engagement both observed and discussed with the participants of this research.

In the proposed framework, therapists are encouraged to consider the person, occupation, and consequences more explicitly than the original framework. Although the original framework does consider these, it was found that these were essential elements of occupational engagement for the participants of this research and as such are placed within the framework as important factors.

Each element of the proposed framework is discussed below to provide a deeper understanding. The pictorial image of the proposed framework is demonstrated in Figure 17 on the following page.

Figure 17: Occupation in Dementia Framework



12.1.i Person

Firstly, it is proposed that the individual (or person) is considered as an important element of occupational engagement. As discussed earlier, there are elements of the self which have a significant impact on participation in occupation, the value of the occupation itself, the intensity of the engagement, and also the consequences experienced. Whilst there are many factors which influence the individual, it was felt that the main elements presented by participants during this research were:

- **Self**: mental health, physical factors, cognitive function, identity, and resilience
- **Social Ecosystem**: peers, family, support systems
- **Environment**: physical environment, access
- **Consequences**: this is the feedback from previous occupational engagement

12.1.ii Occupation

The next element of significance was the occupation itself. There were several elements to occupation which were identified, and as such, this is labelled the prism of occupation to depict the multi-faceted factors which influence whether a person chooses to participate in the occupation or not. The identified elements for participation include:

- Value
- Physical Accessibility
- Difficulty of Task
- Identity
- Skill accessibility

Whilst these are interlinked with the person factors, these are also elements of the occupation itself which can influence whether someone participates.

12.1.ii.a Value:

The value of the occupation is intrinsic to whether someone participates or not. If an individual finds value in the occupation, they are more likely to participate and the greater the meaning, the more intense the engagement. This was discussed in Chapter 8 in greater detail and is linked with the identity the individual and the meaning of the occupation to them. This is very personal and will be different for each person according to their self-identity and their personal history.

12.1.ii.b Physical Accessibility:

This was an important factor for the participants of this study. Not only does this relate to physically accessing the occupation (in terms of place) but it also relates to being able to physically complete the occupation. This was relevant in particular for Fran, Peter, and Sally, all of whom experienced physical inaccessibility with some occupations. Whilst their physical disabilities were a part of this, the occupation itself was also a factor: if this were adapted in the right way for each individual, they may be able to participate.

12.1.ii.c Difficulty of Task

This was an important element of the occupation for the participants of this research. This relates to the challenge or difficulty of the occupation. Whilst this may be linked with the physical or cognitive challenges facing an individual, it is also a factor individually. Indeed, occupations which were significantly challenging (or which were too easy) resulted in non-participation or engagement at a less positive intensity.

12.1.ii.d Identity:

Whilst the identity of the individual is considered in the previous part of the framework, here we consider the occupation itself in relation to the identity of the individual. Participants in the research spoke about the importance of occupations which defined them as individuals, and occupations which challenged this were often not participated in. Conversely, occupations which supported identity, or which supported the evolution of self-identity were more likely to result in participation. This is intrinsically linked with value but is important to be placed as a factor in its own right.

12.1.ii.e Skill Accessibility

In addition to the physical accessibility, attention should also be paid to the skill accessibility. A person may have difficulty participating in an occupation because they do not have the skills to be able to do so. This may be because they have never learnt the skills, or as was the case for participants of this study, they may have lost the skills over time because of cognitive impairment.

12.1.iii Spectrum of Intensity

Following the Prism of Occupation is the Spectrum of Intensity. This is depicted to follow the principle of dispersion, where a light that is shone through a prism splits into the colours of light i.e., a rainbow. It was felt that this pictorially represented the differing intensities of engagement that an individual can experience when participating in an occupation. The design of the spectrum in this way also allows for a more fluid movement between the various intensities which can be used to highlight fluctuations over time or within an occupation. Each end of the spectrum (i.e., red and violet) are the most intense experiences of engagement, with absorption being a positive intensity and repulsion a negative intensity. Participation is a neutral intensity and can be described as the place where a person is present in the moment of the occupation but is not engaged any more than that. The ‘values’ of engagement and disengagement, as proposed by Morris, were removed and replaced by ‘involvement’ and ‘uninvolved’ to avoid further confusion of using the work engagement within the framework itself.

12.1.iii a Etymology of Involvement

In order to ensure that the word ‘involvement’ was correct to use as a replacement for ‘engagement’ within the framework, the etymology of the word ‘involve’ was researched. A search of the word ‘involve’ returned the following definitions:

To have or include (something) as a necessary or integral part or result
To cause to participate in an activity or situation
To be or become occupied or engrossed in something
To be engaged in an emotional or personal relationship

(Oxford Languages, 2021)

The word involve was used in middle English to mean enfold, entangle and to concern oneself (Oxford Languages, 2021; www.etymonline.com).

In comparing these descriptors of the word to the observations and discussions that were held with participants of the study, it was felt that ‘involve’ was an appropriate word to use in this framework. Occupations which resulted in people engaging at this level of intensity saw them being entangled and engrossed in an occupation, but not as much as being absorbed in it. Participants showed a greater engagement than interest, and were more entangled, i.e., concerned with the outcome and consequences of participation.

12.1.iii.b Defining the Uninvolved

In considering the use of the word ‘involved within the framework, the word ‘uninvolved’ was considered for the opposite end of the spectrum. Uninvolved is an antonym of involved, but the meaning and appropriate usage of this term was considered to endure that it was being used appropriately within the framework in accordance with the observations and discussions held around occupation.

The definition of uninvolved is:

> *Not connected with someone or something, especially on an emotional level*
>
> *(Oxford Languages, 2021)*

Feeling or showing no interest or involvement; unconcerned (American Heritage Dictionary of the English Language, 2016)

When considered alongside the observations and discussions of participants, it was felt that disinterest was also an appropriate word to use within the framework. Participants were observed to not show any involvement or concern for occupations and were not connected with the occupation emotionally.

12.1.iv Consequences

The original framework speaks of ‘perceived’ consequences, which implies that a person chooses to participate in an occupation based upon what they believe the consequences will be. Whilst it remained true that perceived consequences were an element of participatory choice, what became apparent during this research was that actual consequences are also imperative to the future participation in occupations. This was most evident for Fran both during the interviews and observations, and indeed indicated that the actual consequences provide a feedback loop which then influences a) whether a person participates in that same occupation again in the future and b) the occupation which follows immediately (in terms of both participation and the value of the occupation). It should be noted that the research for the original framework was conducted in a forensic setting where there was limited choice of occupation, and some occupations were necessary to obtain greater freedoms for the individual, regardless of their value to the individual. This is a fundamental difference between the participants of this research, who not only had their freedom to choose but also had access to a much wider range of occupations on a daily basis (albeit a more reduced choice than they had prior to the onset of dementia and physical health difficulties).

12.1.iv.a Butterfly Effect

The notion of consequences of one occupation directly impacting upon another could be compared to the 'butterfly effect'. This is a term which is often used to explain how a small change in conditions can produce greater differences at a later state. This is based within Chaos Theory which was proposed by Edward Lorenz (1993). When applied to psychology, this becomes

> *"The tendency of a complex, dynamic system to be sensitive to initial conditions, so that over time a small cause may have large, unpredictable effects"*
>
> (American Psychological Association, 2020)

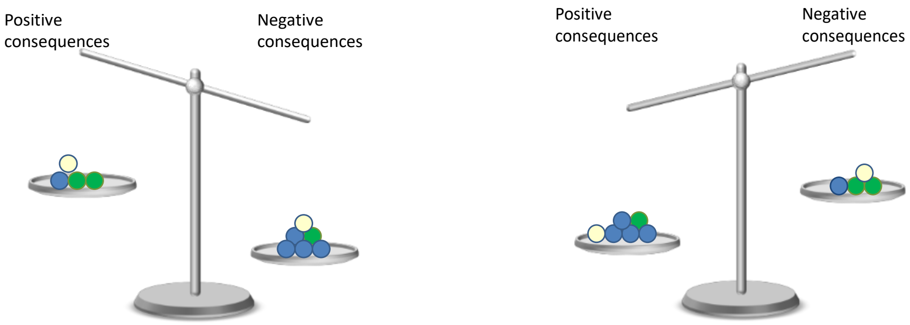
As discussed previously, the factors which influence participation in occupations are complex and dynamic, changing from day to day or even hour to hour for individuals. Consequences are also complex and individual, and small instances within this can have major influences on the individual. This was observed on several occasions over the course of the research. Most notably, Fran was affected significantly by small consequences, and these had significant influences over future occupations. For example, following the singing group when she stated she felt "really high", a member of staff reprimanded her and asked her to be quiet so that another attendee could eat their lunch. This quick conversation had an immense effect on Fran's mood and willingness to participate in occupations for the rest of the day. Ethel spoke about feeling sadness and regret during a group which was discussing childhood holidays, and this consequence affected her ability to participate in future occupations for the remainder of the day and caused her to be low in her mood and upset. Both Fran and Ethel spoke about feeling rushed when getting ready to attend the centre. Both stated that this had an effect on the remainder of the day, making them feel unsettled which meant they could not achieve the more intense engagement. Peter also experienced this during a group where they were discussing movies. He stated that he did not like the morals in the film they were talking about and so stopped participation. This only had the short-term effect on this group though and did not affect his participation for the rest of the day.

McBride (2005) suggests that the core concepts of chaos theory can provide phenomenological support for interpreting complex interactions and can offer insights into why particular consequences occurred. In this research, understanding the complexities of occupational engagement as a whole and the consequences that individuals experience as a result allow us insight into their experiences of living in the world around them and provide an opportunity as therapists to make changes to ensure the consequences are as beneficial to the individual as possible.

12.2 Wellbeing

In the original framework, Morris (2012) provided a description of how participating in occupations with a higher personal positive value and perceived positive consequences results in a greater sense of wellbeing. This was demonstrated using the image of weighing scales, and is shown in Figure 18:

Figure 18: Occupational Balance (Original Framework)



Key:

Blue sphere = positive value

Green sphere = negative value

Beige sphere = neutral value – participation or non-participation

This remains true for the participants of this study, however, given the signs of illbeing shown by some participants at being unable to participate in some valued occupations, for this research a negative weight value would be added to the neutral value occupations, i.e., those in which the person did not participate or was only able to remain at the participatory intensity and was not able to achieve a more intense engagement with the occupation. Acknowledging this by adding a weight value to these occupations reflects the discussions with participants about their sense of loss at not being able to participate in valued occupations or in achieving less intense engagement. This had an impact on the self-identity of individuals in this research and also impacted on mental health. This would also reflect the need for individuals to be encouraged to participate in more occupations which would provide them with positive intensity of engagement over time to instil a greater sense of wellbeing.

12.3 Discursive Revisions

Morris and Cox (2017) also provided a descriptive paragraph to help define occupational engagement. Whilst the framework would apply to those involved with this research, it was felt that some adaptations to this description might provide a deeper understanding of the application of the proposed framework to the participants of this study. The original descriptor was as follows:

> *Occupational engagement is positioned within a framework of personal value and perceived consequences to participation. Occupational engagement is the involvement in an occupation with current positive personal value attached to it. Engaging occupations require more involvement than those occupations that just interest the individual, but not as much as those that absorb them. Occupational engagement is a fluctuating state influenced by complex and multiple internal and external factors. The person will perceive positive or negative consequences to participation, which may change over time in response to feedback from social, cultural, and physical environments. Positive wellbeing occurs when people participate in occupations with both positive personal value and positive perceived consequences for both the individual and the society in which they live.*
>
> *(Morris and Cox, 2017, p.9)*

This description was a good explanation of the premise for the Occupational Engagement Framework. However, in order for the descriptor to reflect the proposed framework and the responses of the participants of this research, some changes are required. Careful consideration of the previous descriptor and challenges to this, plus inclusion of the newer elements found to be important in this research was required. A new preliminary descriptor was identified as this:

> *Occupational engagement is positioned within a complex framework of personal, occupational, and consequential factors. The intensity of occupational engagement can be positive or negative according to the personal circumstances, elements of the occupation and the perceived and actual consequences of participation. The intensity of occupational engagement is a dynamic state which is influenced by complex factors, and which may fluctuate within the occupation or over time, in response to feedback from personal or consequential influences. Positive wellbeing is achieved when people participate in occupations with high personal value, in which they can achieve more positively intense engagement and achieve positive perceived and actual consequences.*

This summarises the dynamic state of occupational engagement and the factors which can influence this, and the elements required to achieve a sense of wellbeing.

12.4 Summary

Having examined the interviews and observations of the participants, it has been identified that occupational engagement is a complicated interaction of a number of factors, and that understanding this helps us to establish the influences on an individual which impact on participation and engagement, and the effects of consequences on the person and future participation and engagement in occupations. The following chapter examines a comparison between the original framework proposed by Morris (2012) and the proposed new framework by considering one occupation for each of the participants of this research.

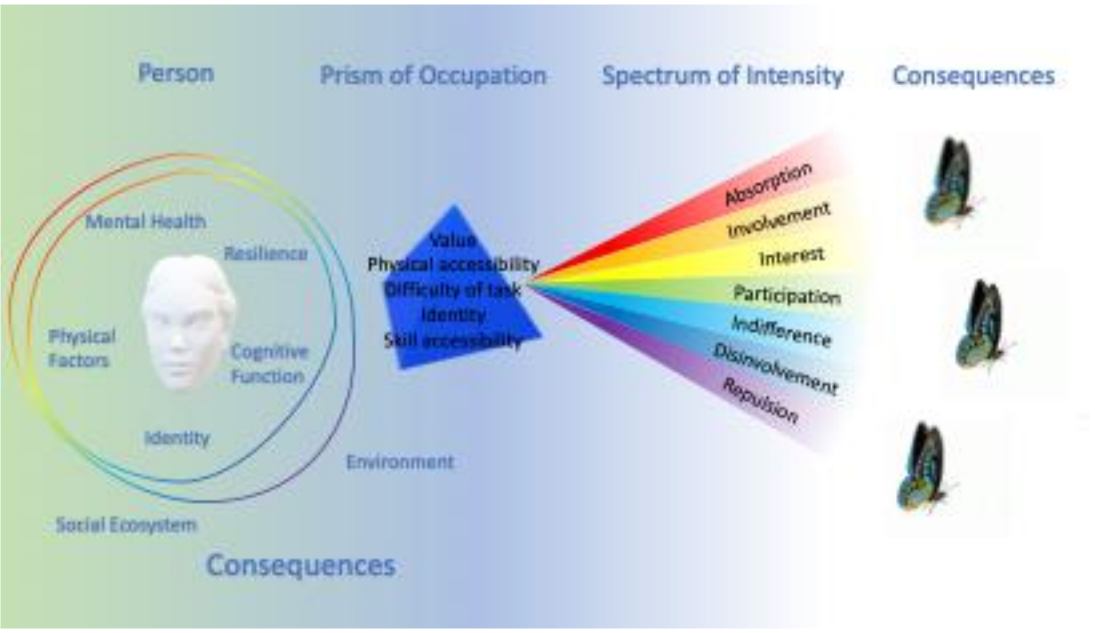
13. Presentation of the Occupation in Dementia Framework

Having discussed the elements of the research which led to a new understanding of occupational engagement for people with dementia, and the factors that contribute to this, and having consolidated this with previous research, a new framework based on the work of Morris (2012) is now presented.

It is proposed that in order to facilitate positive occupational engagement and maximise positive consequences, personal and occupational factors should be considered. In doing so, the therapist can work with individuals with dementia to increase the positive intensity of engagement in occupations to achieve more positive consequences, which then result in a greater sense of wellbeing for the individual.

The overall framework proposed is presented pictorially as follows:

Figure 19: Occupation in Dementia Framework



The context of this framework is provided below, adapted from that provided by Morris (2012):

Occupational engagement is positioned within a complex framework of personal, occupational, and consequential factors. The intensity of occupational engagement can be positive or negative according to the personal circumstances, elements of the occupation and the perceived and actual consequences of participation. The intensity of occupational engagement is a dynamic state which is influenced by complex factors, and which may fluctuate within the occupation or over time, in response to feedback from personal or consequential influences. Positive wellbeing is achieved when people participate in occupations with high personal value, in which they can achieve more positively intense engagement and achieve positive perceived and actual consequences.

Figure 20: Occupational Balance and Wellbeing

Key:

Blue sphere = positive value

Green sphere = negative value

Beige sphere = neutral value – participation or non-participation in non-valued occupations

Red sphere = non-participation in valued occupations

This diagram has been adapted from that designed by Morris (2012). The elements of occupational balance were found to be similar, with participants reporting a greater sense of wellbeing from involvement in occupations with more positive consequences, and a greater sense of illbeing when participation in occupations resulted in more negative consequences. However, as previously discussed, an additional sphere has been added to demonstrate the impact of consequences from being unable to participate in valued occupations. The scales on the right demonstrate wellbeing, and the scales on the left, illbeing. As is clear from the distribution of the spheres, with wellbeing there are more spheres with positive consequences and fewer with negative consequences or non-participation in valued occupations. The illbeing scales demonstrate that the balance is distributed more in favour of occupations with more negative consequences and non-participation in valued occupations.

14. Comparison of the Original Framework to the Proposed Framework

In this section, case studies of occupations to demonstrate the framework in action. This is to demonstrate the use of the framework in action, as it would be used in occupational therapy practice. The occupations have been considered from an occupational therapy perspective, and the two frameworks considered for each occupation in order to demonstrate the increased depth that can be obtained in applying the proposed framework. The original Occupational Engagement Framework is applied to one occupation per participants, followed by a discussion about the focus provided by applying the proposed framework resulting from this research. The original framework does not explicitly consider these factors within the pictorial explanation of the framework, whereas the proposed framework invites the reader to consider these for each individual. Occupations which were discussed in the interviews are considered here as they provide the greatest insight into the occupation from the participants' perspective. Some were observed at the centre but not all as some occupations that the participants valued the most were carried out away from the centre. The original framework was used during discussions and observations to try and establish the 'value' of the occupation. This is terminology used by the original framework and as discussed in Chapter 8, use of the word 'value' is questioned by this research. Observations and discussions were analysed using the original framework which helped to determine whether the participant found the occupation engaging, interesting, repulsive etc. Observation forms completed for those occupations which were observed can be found in Appendix 6. Please note that the language proposed for the new framework will now be used unless the original framework is being discussed.

14.1 Fran: Baking

Fran participated in a baking activity at the centre. She was observed to participate in this and also spoke about it in her interviews, considering it to be a valued occupation which provided positive occupational engagement and mostly positive outcomes.

14.1.i Original Framework:

Observations and conversations with Fran about this indicated that she found the baking an occupation with positive value. Initially, this was an engaging occupation, but as the session progressed the positive value reduced, and she found it less engaging and more interesting. This was demonstrated in observations where she became less able to take part in the baking but remained a participant. Fran also spoke about this in her interviews, describing how her pain levels increased, meaning she was not able to carry out some of the tasks in the occupation. Fran experienced some positive consequences from this occupation (learning new information, taking a baked item home to her husband to enjoy, positive mood, sense of achievement) but also the negative consequence of pain. If Fran were to participate in more occupations which provided her with these positive consequences, but the pain was managed she would experience a greater sense of wellbeing.

14.1.ii Proposed New Framework:

If we apply the proposed enhanced framework to the same occupation, we begin to understand a little more about Fran, why she participated in this occupation, her intensity of engagement and the consequences of participating in the occupation.

14.1.ii.a Person

If we begin by considering the person, we know from the interviews and observations that several factors affect Fran’s participation in occupations. These include low mood (mental health), pain from arthritis (physical health), her cognitive impairment from her dementia diagnosis (cognitive function) and that she is extremely resilient and tries to find ways around her difficulties and challenge the inevitable deterioration of her cognitive abilities. We also know that Fran is striving to maintain her identity, especially as she has lost the ability to participate in some occupations which support her personhood. Some of these factors inhibit her participation in some occupations, but her resilience motivates her to participate in new occupations which encourage new learning especially. Occupations which are within her personal limits, but which support her identity and embrace her resilience are particularly attractive to Fran.

Fran's social ecosystem when considering the baking activity include her husband (she takes the baked items home for him to share), her sister and daughter (who provide her with praise for participating in the occupations), her friends and peers at the centre who support her identity, and the staff at the centre who help facilitate the occupation.

Environmentally, Fran described some situations where she can feel disorientated, therefore familiar environments can support her participation in occupations. The day centre is a familiar and safe environment for Fran to participate in occupations.

14.1.ii.b Prism of Occupation

Baking is a meaningful and valued occupation for Fran: she stated that she enjoys making tangible items that she can take home to her husband, and she assigns a higher value to occupations which encourage new learning (she considers baking to be a new occupation to her). Staff at the centre make the occupation physically accessible to Fran – they adapt the occupation so that Fran can participate, taking into account the limitations of her arthritis. Staff at the centre also grade the occupation accordingly so that Fran can manage the occupation cognitively, ensuring that the occupation is within her skill range. The occupation itself is also graded to ensure that it is not too complex or difficult, ensuring that Fran is able to achieve what they set out to achieve (e.g., making buns and not baked Alaska).   In terms of identity, the occupation supports Fran in learning a new skill and proving that her physical and cognitive difficulties don’t define her.

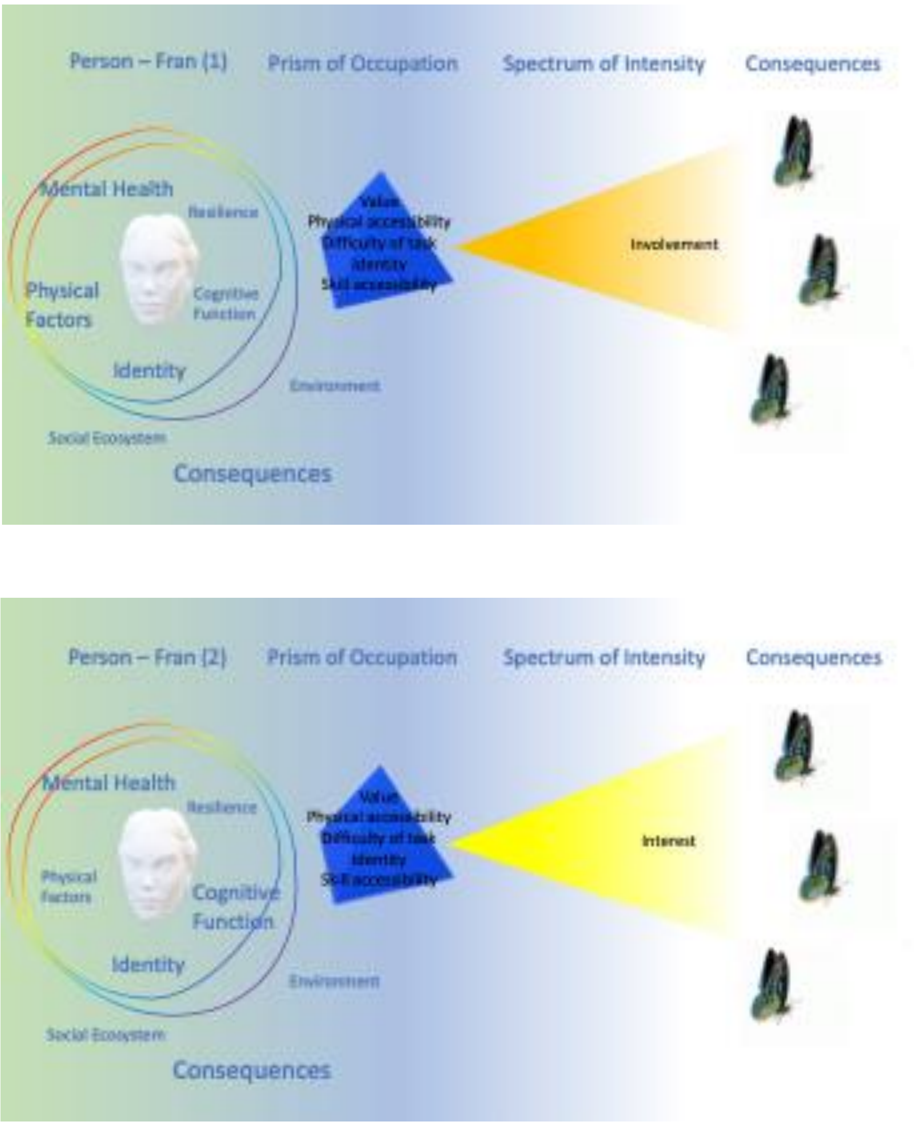
14.1.ii.c Spectrum of Engagement and Consequences

During this occupation, the spectrum of engagement for Fran was variable. During the first half of the occupation, Fran found the occupation involving – she was actively involved in the occupation and was observed to be active in weighing and mixing the ingredients. However later, the occupation became more interesting than involving. This was linked explicitly with the consequences of her participation in this occupation. Being involved in the occupation resulted in consequences which saw an increase in her pain levels from the arthritis. The positive consequences of the occupation (improved mood, sense of achievement, affirmation of her ability to engage in new learning, making tangible items to share with her husband), ensured her motivation to continue participating, but her engagement became less positive and changed to interest. At this point, she was observed to sit back and watch the other group members complete the occupation but remained active in talking about the baking and remained interested in the outcomes. This demonstrates that the consequences of participating in this occupation for Fran had a direct impact within the occupation itself, indicating that immediate consequences within the occupation should be considered in addition to those evoked following the occupation. This would allow the therapist to adapt an occupation whilst the individual was participating and would allow the therapist to plan for a potential change in engagement to ensure the most positive consequences were achieved.

Fran’s continued participation in the occupation ensured that the consequences remained positive overall. Her change in engagement ensured that her pain was limited overall but allowed her to gain a sense of achievement, make something she could take home to share with her husband, promoted a positive mood, and supported her personhood.

The pictorial version of the framework applied to Fran's baking occupation is demonstrated in Figure 21.

Figure 21: Fran Baking



The implications of applying this framework to Fran are that we begin to understand the influences on Fran as a person and how these support or inhibit her participation in occupations. We then begin to understand the facets of the occupation itself which promote participation so that we can ensure the occupation is meaningful and optimal for participation. The spectrum of engagement allows us to understand whether the participation provided a more positive or negative engagement. This is important to recognise because, as recognised by Morris (2012), participation in occupations with positive engagement and positive consequences provide a greater sense of wellbeing. Finally, knowledge of the consequences of the occupation provide information about the continued participation in an occupation at the time and for future occupations, as well as providing insight into whether the occupation promotes wellbeing overall.

14.2 Brian: Colouring

Although not observed at the centre, Brian spoke about colouring being one of his most valued occupations. He provided a lot of information and detail about the colouring work that he did at home and during an art group that he attended and brought work to show me during my time at the centre, which further indicated the importance of this occupation to him.

14.2.i Original Framework

When the original framework is applied to Brian's art, we can see that he finds this an absorbing occupation, making the value very positive. The consequences he experiences from this are also positive: it supports his identity and sense of self, increases his confidence, and lifts his mood. We know from applying this framework that if Brian participates in this occupation and others which provide similar positive consequences, he will experience a sense of wellbeing.

14.2.ii Proposed Framework

Applying the proposed framework to the art occupation allows us to understand more about the value of the occupation and why he finds this an absorbing occupation.

14.2.ii.a Person

The person factors which influence Brian are key to his participation in occupations.

Identity

Brian spoke a lot about his previous identity, and the importance of occupations in supporting this. The loss of valued occupations was devastating for Brian and had a huge impact on his sense of self. This loss had an impact on Brian's mental health – he spoke about how he felt depressed because he could no longer participate in valued occupations, and this was reflected in his tearfulness whilst talking about it. Occupations which support his identity and sense of self are likely to be more attractive to Brian and therefore he will be more willing to participate. Brian also has some physical health issues, particularly around his mobility, which make some occupations difficult. In addition to his mental and physical health factors, Brian is also trying to manage cognitive impairment caused by dementia. This too affects his ability to participate in some valued occupations and is an important consideration in his participation in occupations.

Brian's wife is a pivotal element in his social ecosystem. He spoke about their relationship in great detail, and about how she provides him with support in participating in occupations which allows him to maintain a sense of independence and supports his identity. She accompanies him to some occupations, including the art class, and he feels a sense of pride in watching her skills develop. This is important to Peter and the consequence of watching his wife develop her own skills instils a sense of pride and pleasure and encourages him to participate in further occupations with his wife. Peter also spoke about the art class instructor, who has provided encouragement and help in achieving results that he can be proud of.

With regard to environment, Brian requires a space which allows him to work within his physical capabilities. The art class takes place in a space which facilitates Brian's physical abilities so that he can participate in the occupation.

14.2.ii.b Prism of Occupation

In understanding the personal influences affecting Brian, we begin to develop an insight into the meaning of this occupation to him. The occupation supports his identity and sense of self and is an occupation he can enjoy with his wife, therefore making it more valued. This makes it a more attractive occupation for him and therefore encourages participation. He is able to access the occupation through his wife as she drives him to the venue. The facilitator ensures that Brian is able to access the art, providing the equipment he requires. The difficulty of the task is variable, and Brian can adapt this according to his own skills. Brian talked about (and demonstrated) his skills in colouring the pictures in detail and described the effects he was trying to achieve. He explained how he had developed his skills over time and how this was really satisfying for him.

14.2.ii.c Spectrum of Engagement

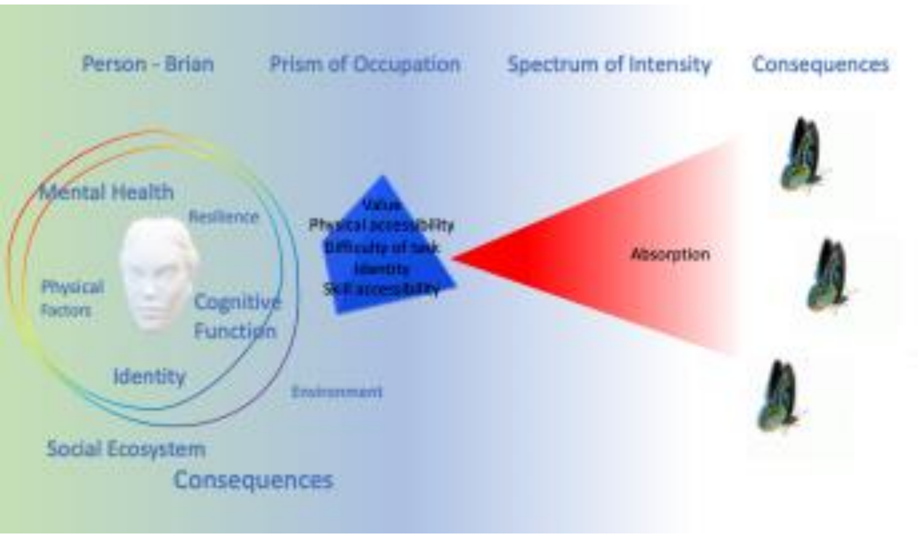
Although Brian was not observed to participate in this occupation, his detail in the descriptions about this and the quality of the pictures he showed me indicate that this is an absorbing occupation for Brian. He became engrossed in the detail when speaking about it and described the effects he was using to try and depict movement in the water of the picture, which further suggests that this was absorbing for him.

14.2.ii.d Consequences

The consequences of participating in this occupation for Brian are very positive. The colouring allows him to express himself and supports his changing identity.

He finds a sense of purpose and personhood in creating pictures and finds achievement in finishing a picture with the detail he intended. This promotes a sense of wellbeing and improves his mood, which encourages him further to participate in this occupation. Brian also finds positive consequences in participating in the occupation with his wife: he enjoys spending quality time with her and described a sense of pride in watching her develop her own skills and create works of art. Figure 22 below demonstrates the occupation pictorially.

Figure 22: Brian Colouring



14.3 Sally: Sewing

Sally spoke about how she had previously participated in sewing over the course of her life and that she had made clothes previously. She was observed to participate in a sewing group at the centre and spoke about this during the interviews.

14.3.i Original Framework

The original framework would posit this occupation as an engaging occupation for Sally. She was observed to be very involved in the activity and was concentrating on the task, making a humming noise as she participated. She was asking questions throughout on the next steps and made good progress with the item she was sewing. The consequences of this for Sally were not clear, as she did not demonstrate any positive or negative changes immediately afterwards, although it could be assumed that they were neutral or more positive than negative.

14.3.ii Proposed Framework

Applying the new framework to this occupation and Sally provides us with a little more insight into the engagement and the consequences of this occupation for her on this day.

14.3.ii.a Person

The information gained from Sally during the interviews tells us that Sally had been experiencing a challenge to her self-identity at that time. Her family had well-meaningly stopped her from participating in many occupations because the risk to her physical health, she was in the process of moving from her family home to a new sheltered accommodation flat, and she had been challenged to accept changes to her appearance in using a walking aid, which made her feel like an "old lady" rather than the person she identified with. Sally has participated in sewing in the past and has made clothing items for herself and family, which supports her identity and sense of self. We also know that she was experiencing a period of ill-health, and her mobility was poor along with experiencing chest problems. During the interviews, Sally stated that he was feeling unwell at the time of the sewing activity and that this had a significant impact on her engagement and also the consequences. Additionally, she was low in her mood and very anxious, which was the reason for her attending the day centre. Sally had also received a diagnosis of dementia, which indicates that she was experiencing a deterioration of her cognitive function. In order for her to participate in the occupation of sewing, it would be necessary to ensure that these factors were accommodated in order to make it attractive and to ensure that she was able to participate to her best ability.

14.3.ii.b Social Ecosystem

Sally was well supported by her daughters, and they ensured that she continued to attend the centre to increase her opportunity to participate in occupations with a positive consequence and hopefully increase her wellbeing. Sally stated in the interviews that she was beginning to feel more positive since she began attending. She stated that she found some days more positive than others and did not like attending on the days where there were fewer women, indicating that she prefers the company of women and is more motivated to participate in occupations on those days. The staff at the centre provide her with encouragement and support in participating in occupations, ensuring that she is able to achieve something positive during the activity sessions.

14.3.ii.c Environment

Sally stated in her interviews that she finds the environment of the day centre positive and that she feels supported and content there. This will provide a more encouraging atmosphere for her to participate in occupations.

14.3.ii.d Prism of Occupation

The sewing occupation holds value for Sally as this was something that she was previously proficient in doing. The sewing activities provided her with a tangible item to make, which was more motivating for Sally (they were making an apron). Staff at the centre ensured that the sewing was physically accessible to Sally, ensuring that she had all items available and that she was able to sit down where necessary. Staff also ensured that the sewing was cognitively accessible, breaking the task down into manageable parts and providing support where required. The occupation itself is one which is familiar to Sally and one that she has participated in previously for her own pleasure and enjoyment, and therefore it is more likely to support her identity, making it a more attractive occupation for her to participate in. She is also skilled in sewing and therefore, assuming correct support is provided, should be able to participate in this occupation drawing on these previously learnt skills.

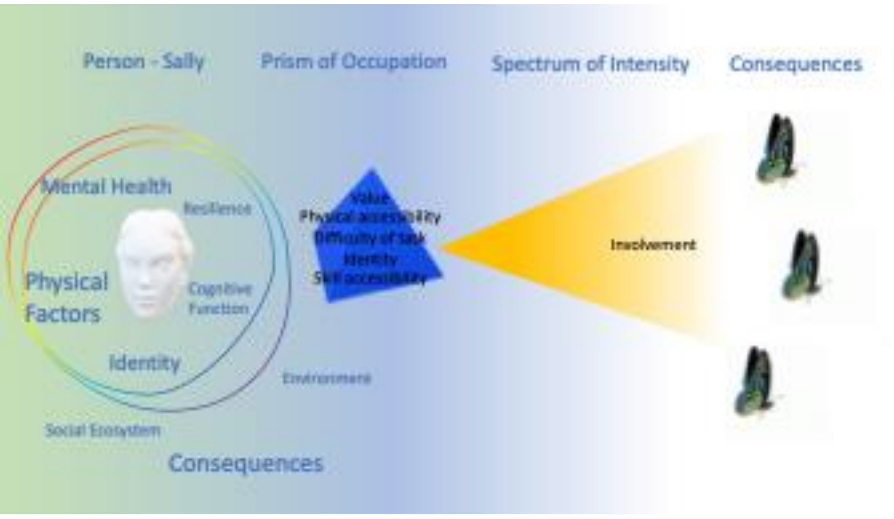
14.3.ii.e Spectrum of Engagement

Observations of Sally in this occupation indicated that she was mostly involved in this occupation. She was seen to be taking part and was humming as she concentrated and asking what the next steps were. She was involved in sewing the fabric and in working towards a finished apron. However, the complexity in this arises from knowledge about Sally's physical health at that time, where she stated that she was not as involved as she could have been because she was feeling unwell. This gives us knowledge into the occupation in that had her physical health been better she would have found this a more involving or even absorbing occupation, meaning that it remains a worthwhile occupation for her to participate in but would have more positive consequences if her physical health were improved. This also would explain why at times the occupation was ambivalent or even disengaging for her, although these were momentary and on the whole it was an involving occupation.

14.3.ii.f Consequences

Sally stated that she had enjoyed the sewing, although not as much as she potentially would if she was well, which does indicate a positive consequence for her if not as positive as it might have been. This suggests that a review of her physical health might lead to greater occupational engagement and more positive consequences (and therefore wellbeing). Whilst this might seem an obvious point to make, the framework provides some evidence to support this and would assist healthcare professionals in identifying how to optimise her participation and engagement in future occupations. Figure 23 below demonstrates the occupation pictorially.

Figure 23: Sally Sewing



14.4 Peter: Mindfulness Colouring

Although not observed at the centre, this was a key occupation for Peter which he spoke about whilst I was with him at the centre and in part during his interviews.

14.4.i Original Framework

The original framework would place this occupation as an absorbing occupation for Peter (based on what he said about the occupation) and that the consequences were very positive for him in lifting his mood and sense of purpose. This has led to a significantly increased sense of wellbeing for Peter.

14.4.ii Proposed Framework

Application of the proposed framework to Peter’s colouring serves to provide a more detailed understanding of his motivation for participating in occupations and the consequences that encourage him to continue.

14.4.ii.a Person

Peter explained in the interviews that he is a very spiritual person. He has a strong faith and described himself as a devout Christian. Peter spoke about how many of his valued occupations are linked with his faith, and how he chose not to participate in occupations which did not align with his values. This is a crucial element of Peter’s identity, and therefore it is important that any suggested occupations support this. The colouring activity is very much linked with his identity: not only did he enjoy the colouring, but he then framed them with frames bought from charity shops and donated them to the centre for the staff to sell to raise funds to help them provide a service to others. This allowed Peter to feel that he was continuing to do good work and promoted his participation in the occupation. It also encouraged him to complete the work to a high standard so that others will want to buy the works. Peter had a diagnosis of vascular dementia, which affected both his cognition and his physical health. He had become unable to participate in many occupations that he previously enjoyed because they became too difficult, so it was important that current occupations were accessible for him.

With regards to mental health, Peter was a very positive at the time of this research and his mood was good. This has a positive effect on his willingness to participate in occupations and he was observed to be keen to join in on most activity groups at the centre.

Peter’s social ecosystem is a major contributory factor not only in his participation in occupations, but also in supporting his identity. His wife ensures that Peter is able to access occupations by taking him to the venues where they occur. At the time of the interviews, Peter was attending the centre and was also still active with the church. His wife supported him in accessing these and in facilitating his participation in the occupations. She also ensured that he was presented in the way in which he always chose, wearing a shirt and tie. Both Peter and Fran commented in the interviews that he always wore a shirt and tie, and that this was his identifying factor. In ensuring that he was dressed in the way that he always chose, she was supporting his personal identity. The church that Peter attends are part of his social ecosystem, influencing his participation in some occupations, and influencing his identity. The people he interacts with as a part of this also support his participation in occupations whilst attending church activities. In addition, the staff at the centre were an important part of his social ecosystem at the time of the research: they encouraged him to participate in occupations whilst attending and also gave his colouring a purpose whilst at home.

The environment had an important place in Peter's participation in occupations. The church provided him with a familiar environment which facilitated his participation. The centre provided him with an environment which was supportive but also which was appropriate in terms of noise, lighting, and space to facilitate his participation. For the occupation being considered here, he mainly participated at home, which is familiar, and he has access to all the items he requires to carry out the colouring in his own time.

14.4.ii.b Prism of Occupation

The colouring held a lot of value for Peter. Not only was it an occupation that he found relaxing and pleasurable, but it allowed him to raise funds for what he believed to be a worthy cause. This was also supporting his identity in allowing him to continue his charitable work, which is founded in his faith. It was an accessible occupation both physically and in terms of his skills: he was able to participate in his own familiar environment which met his needs in terms of his physical difficulties and his cognitive impairment. It was an occupation which was not too demanding, and he could adapt to his own requirements whenever needed, ensuring that it was not too difficult for him to complete.

14.4.ii.c Spectrum of Engagement

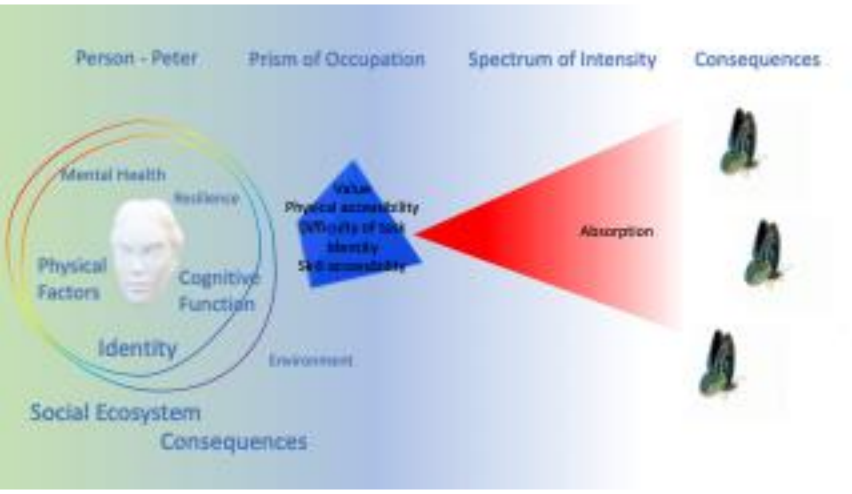
Although Peter was not observed participating in this occupation, his description of the efforts he put into it were so detailed that it was assumed this was an absorbing occupation for him. He showed me the pictures he had completed and explained how he tried to work out the colours so that they complimented each other, and how he worked hard to put the detail into the pictures. Staff at the centre agreed that he becomes engrossed in the colouring and that they encourage him to do this at the centre when he is having difficulty with other occupations.

14.4.ii.d Consequences

Peter stated that he gained a lot of pleasure and enjoyment from participating in the colouring. He also showed pride in his work and took me to see the framed pictures that staff had hung on the walls of the centre. Peter provided me with some examples of his work and encouraged me to use them for this research, and as such the images are used in between the chapters of the thesis. In addition, the colouring provided him with a sense of purpose in that he was donating them for sales to raise funds for the centre. This also fosters his self-identity, allowing him to continue his good work for charity and supporting his spirituality.

Applying the proposed framework to Peter and this occupation helps us to understand his motivation for participating and also how the consequences promote his continued participation on a regular basis. This occupation is also closely linked with another occupation (buying frames from charity shops) and his attendance at the centre, even though he participates in the occupation away from the centre. In turn, this would allow therapists to identify occupations which would have similar motivational qualities and would have similar consequences. Figure 24 below demonstrates the occupation pictorially.

Figure 24: Peter Colouring



14.5 Ethel: Holiday Reminiscence

Ethel was observed to have difficulty participating in many of the activities at the centre, as she was often preoccupied with concerns about her health, hospital appointments or things at home. She was observed to participate in a shopping trip which was a very positive experience for her. However, her comments in the interviews about the reminiscence group she participated in were very poignant, and a deeper understanding of her circumstances allows us to identify issues which might affect participation and the consequences from particular occupations.

14.5.i Original Framework

Based on the observations of this occupation, Ethel found this to be a repulsive occupation. She was very negative, and although she was listening and responding to some conversations she sat with her eyes closed throughout most of the session. Ethel stated that she had not enjoyed the occupation and the consequences were negative for her, having an impact on her mood and general demeanour.

14.5.ii Proposed Framework

The proposed framework allows us to delve deeper into Ethel's reaction to this occupation in order to understand why it was repulsive and how it could be adapted for her in the future.

14.5.ii.a Person

Ethel was very family orientated, and throughout the interviews spoke about the loss of her husband and her son. She also spoke about the loss felt when occupations were no longer required e.g., knitting jumpers for her sons. She identified as a strong and determined lady who, prior to the onset of her physical and cognitive difficulties, was very independent. Physically, she had poor mobility and at the time of the interviews had received a diagnosis of breast cancer. She was also very anxious and low in mood, which had a significant impact on her ability to participate in some occupations. Cognitively, Ethel did not believe that she had much difficulty, although this was apparent in some of the occupations she was observed to participate in. Ethel's mental health and the loss of her family (husband and son) were a great influence on her engagement in this occupation. During discussions about the occupation she stated that she had found it very upsetting because reminiscing about holidays in the past made her think about the lovely experiences she had in the past that she will never experience again. This sense of loss was immense and is a demonstration of how the consequences of participating in an occupation can have an impact within an occupation and influence engagement. She continued to participate in the occupation, however it became an increasingly repulsive occupation because of the feelings it evoked in her.

Ethel's social ecosystem comprised of many third sector agencies, including her home carer and the staff at the centre. They ensured that she was able to attend the centre in order to participate in occupations such as the reminiscence. She did have some support from her surviving son and grandchildren, but this is limited. Ethel did also recognise that she has some support from neighbours, who helped her to access hospital appointments and go shopping occasionally. For this occupation, staff at the centre encouraged her to participate and provided reassurances for concerns she had in order to maximise her potential to achieve positive engagement and consequences. Ethel's peers at the centre were also part of her social ecosystem and influenced her participation in occupations. During the interviews, she spoke in terms of 'us and them' and referred to herself as being different to the other attendees. She sometimes found this frustrating and did not wish to engage much with others at time. Ethel sought out the staff at the centre for company and reassurance rather than others who were attending.

Environmentally, Ethel described the centre as being difficult at times. She found it stressful being away from her home, as this raised concerns about where she had left her bag/purse and whether her belongings were safe. She also found it difficult to be around her peers, as she did not feel that she had anything in common with them. The environment for the reminiscence was not particularly helpful for Ethel as it was a group situation, and she may have preferred to reminisce on a 1:1 basis as she did during the interviews. This may be an important factor when encouraging Ethel to participate in such occupations as she may have more positive engagement and consequences if these were carried out on an individual basis.

14.5.ii.b Prism of Occupation

When considering the value of this occupation for Ethel, it was apparent that the group reminiscence did not hold much personal value for her. The topics were generic, and a more specific topic to her may have resulted in more positive engagement and consequences. There was little physical or skill difficulty in the occupation, which may again have been a source of frustration for Ethel, who likes to feel purposeful as this supports her identity as a capable lady. The occupation also served as a reminder of her past identity as a mother and wife, and the realisation of the loss of this through reminiscence was a devastating effect on Ethel, and made the occupation less appealing. This is a direct consequence of participation and is a further demonstration of how consequences can change engagement during an occupation. She did continue to participate though, although this may have been a result of feeling that it was necessary because it was part of attending the centre (this is assumed though and was not confirmed through interview).

14.5.ii.c Spectrum of Engagement

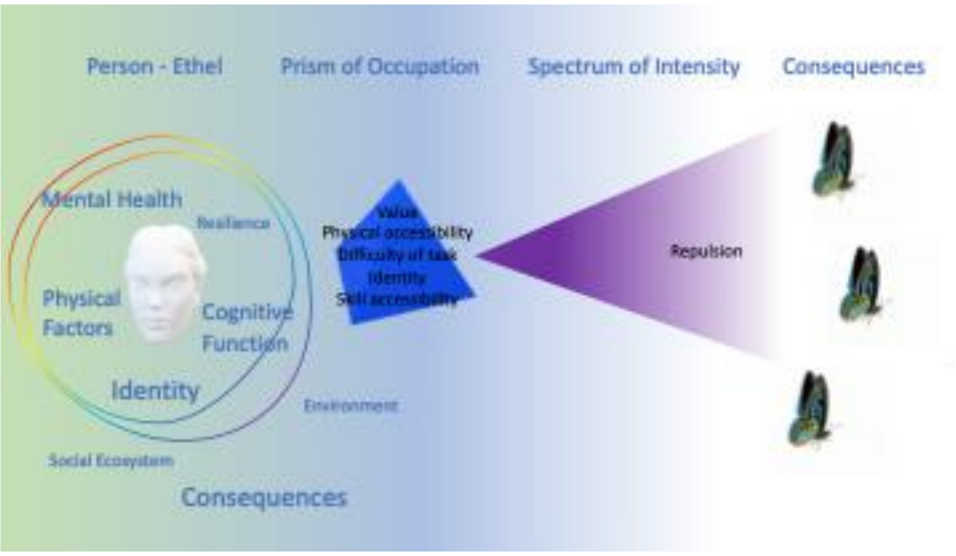
Observation of Ethel in this occupation indicated that she found this a repulsive occupation. She initially willingly went into the group, however as time passed and the consequences of reminiscing arose, her engagement became more negative.

14.5.ii.d Consequences

This occupation definitely resulted in negative consequences for Ethel. She became very sad and mournful about the loss of her family members and her loss of role and identity as a wife and mother. The consequences impacted on Ethel's engagement during this occupation, making it much more negative than it might have been otherwise. These consequences also had a negative effect on future occupations during that day as Ethel felt very low for some time afterwards.

This analysis of the reminiscence provides a huge insight into what was happening for Ethel and how this occupation might have been adapted to make it a more positive experience for her. We understand more about her identity and her current physical and mental health, how she is generally supported and also how the occupation itself might have been adapted for her. Had this occupation been carried out on a 1:1 basis and been focussed on Ethel's personal experiences, she may have enjoyed speaking about her memories of holidays with her husband and sons, rather than generic discussions leading to increased feelings of loss (of people, role, and identity). Figure 25 below demonstrates the occupation pictorially.

Figure 25: Ethel Reminiscence



14.6 Tony: Cooking

Tony was observed to participate in several cooking groups during the research. He spoke highly of these during the interviews, and they were occupations with positive engagement and positive outcomes for him.

14.6.i Original Framework

The original framework would tell us that Tony found the cooking to be an engaging and absorbing occupation (depending on the stage of the process). This was positive engagement with positive outcomes: Tony felt a sense of achievement in making something and taking it home to his wife, which lifted his mood.

14.6.ii Proposed Framework

Applying the framework to this occupation for Tony helps us to understand what it was about this occupation that made the engagement and consequences so positive, so that this can be applied to future occupations. In doing so, we might find new ways of encouraging participation in positively engaging occupations to promote an increased sense of wellbeing.

14.6.ii.a Person

Tony described himself during the interviews as a very capable man. He spoke about his career and his hobbies, and also spoke a lot about his resilience to his physical and cognitive difficulties and how he tries to overcome these. He spoke about how he enjoyed learning new skills, and this supported his self-identity. Tony had previously had a cerebrovascular accident, which had left him with some residual mobility difficulties and word-finding difficulties, meaning that conversation could, at times, be difficult. Cognitively, Tony had experienced changes following the cerebrovascular accident, but he had been working hard to overcome these. Mentally, Tony was well at the time of the interviews, however he did discuss previous feelings of low mood that had reduced his motivation to participate in occupations. This would need to be a consideration when planning future occupations with Tony to ensure that his mood was not affecting his ability to participate.

Tony was well supported by his wife, who helped him to access venues so that he could participate in occupations. She brought him to the centre and also took him to other venues to access things such as physiotherapy groups. He was also supported by other family members (his sons) who encouraged him to attend. At the centre, he was influenced and supported by staff and his peers, who helped ensure that occupations were accessible. Outside of the centre, he also had peers via his radio hobby whom he communicated with regularly. These helped to lift his mood and provided a connection to his identity.

The environment at the centre was supportive for Tony, allowing him space to mobilise on a level surface with no steps. He was able to sit and stand accordingly during the cooking.

14.6.ii.b Prism of Occupation

During the interviews, Tony stated that the cooking held value for him as it allowed him to learn a new skill and to take home a meal for his wife to enjoy with him, and gave his wife a night off from cooking. It supported his identity by allowing him to prove that he was capable of making something that he has never made before and proving that he was capable. The cooking is physically accessible as he can do part of it sat down and part stood up, allowing him to rest if needed. The recipe was broken down into manageable parts by staff at the centre, which minimised the difficulty of the occupation, and he was able to learn new skills with the support of the staff.

14.6.ii.c Spectrum of Engagement

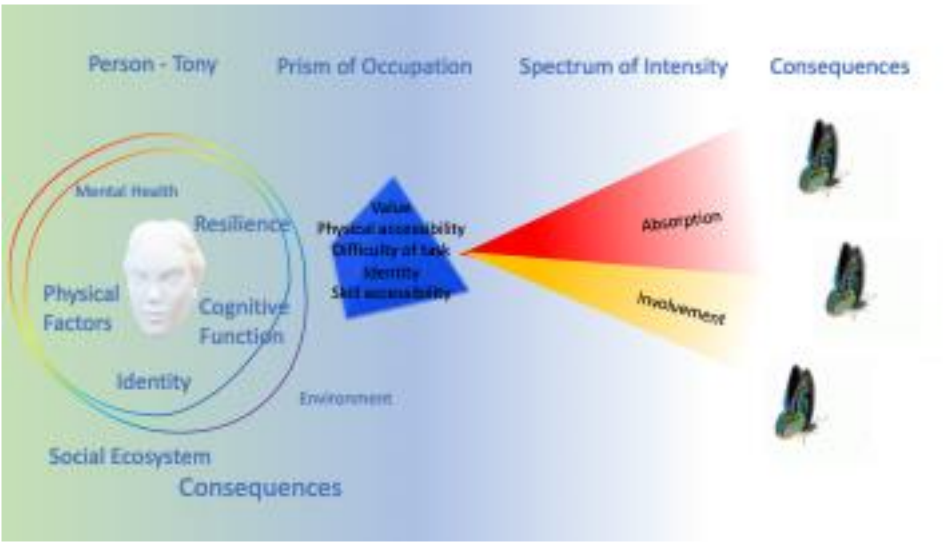
Tony found the preparation of the food for the recipe involving. He was observed to peel and chop the vegetables, discussing the process with staff as he progressed. As the process moved from preparation to cooking, Tony became more absorbed in the task. He stood at the cooker with the pan, stirring it and giving it his full attention.

14.6.ii.d Consequences

Tony stated that he enjoyed making the food, in particular that he was learning something new. He stated that taking the food home to share with his wife was a really positive experience and that they both relished eating something different. This lifted his mood and encouraged him to participate in other new occupations at the centre. This also supported his identity of being a capable gentleman and gave him a sense of achievement and satisfaction.

In understanding what motivates Tony to participate in the cooking group, we can begin to develop knowledge about other occupations that Tony might like to participate in: he enjoys making things, in particular tangible things that can be shared with his wife. He also likes to learn new things and challenge his abilities – this was also evident in the interviews when he was speaking about participating in occupations that others thought he shouldn’t or could no longer do, and when he was speaking about re-learning how to broadcast on his radio. Figure 26 below demonstrates the occupation pictorially.

Figure 26: Tony Cooking



The differing spectrum of engagement factors have been shown together here as they are combined within the different parts of the occupation according to the task and did not change according to feedback from the consequences as with Fran.

15. Review of the Literature on Occupational Engagement

As this research is proposing a new perspective on occupational engagement for people with dementia attending a day service, it was considered that a review of recent literature on occupational engagement would be beneficial to consolidate the findings. The original research conducted by Morris (2012) considered the definitions of occupational engagement at that time, however it was felt necessary to review more current research and definitions of the term to further embed this research into the current thinking on what occupational engagement is and how this relates to occupational therapy practice. This also serves to strengthen the argument for the development of the new framework.

A search of the terms ‘occupational engagement’ and ‘definition of occupational engagement’ returned several articles within the past 10 years which attempted to explain what occupational engagement is and how the term is used within occupational therapy practice. One of the most significant papers highlighted attempted to clarify the construct of occupational engagement. Kennedy and Davis (2017) explored the understanding of occupational therapists of the term occupational engagement. They argued that occupational engagement is a term with a broad range of definitions in practice, and that this is problematic when attempting to conceptualise it as a core element of practice. Kennedy and Davis (2017) demonstrated that there is confusion around the terminology used within occupational therapy practice and that the term occupational engagement lacks a clear definition and is often used interchangeably with terms such as participation and performance.

Similarly, Black et al. (2019) argued that the lack of a solid theoretical definition of the term occupational engagement presents challenges to practice, especially as it is a construct which underpins the profession. In the United Kingdom, the Royal College of Occupational Therapists describe occupational therapists as being concerned with the facilitation of occupational performance/engagement (RCOT, 2020). The American Occupational Therapy Association (2014) define occupational engagement as being an interaction of the body, mind, and spirit, and this underpins the practice of occupational therapy. And in Canada, the notion of occupational engagement is clearly positioned as central to the profession by the development of models of practice (i.e., Canadian Model of Occupational Performance and Engagement (CMOP-E) (Kennedy and Davis, 2017; Black et al., 2019). This demonstrates the centrality of the concept to occupational therapists, however a true definition of what occupational engagement is and how it can be measured remain elusive and ambiguous.

Black et al. (2019) conducted a systematic review of the term ‘occupational engagement’ and found that within the varying definitions of the term, six core themes emerged. These were: active involvement in occupation, finding meaning and value, subjective experience of engagement, social and environmental interactions, balanced engagement, and developing identity through occupation. These definitions were fragmented and inconsistent, with only one study including all of these six elements (Black et al., 2019). This study was conducted by Bejerholm and Eklund (2007) and encapsulated occupational engagement as something which occurs over time and involves a dynamic interplay between personal, occupational, and environmental factors. Jackman (2014) argues more simplistically that occupational engagement is the *manner* in which a person performs an occupation and is more related to the degree to which a person involves him/herself in the task. Jackman (2014) also argues that occupational engagement is intrinsically linked with a sense of being and presence, making it different from the concept of participation or performance in an occupation as this implies simply taking part.

Interestingly, a search through existing literature found a paucity of research around what occupational engagement is for people with dementia. References were made to previous research which sought to define occupational engagement, but as discussed this is focussed on recovery, which is not the primary focus of therapists working with people with dementia. Instead, the literature focussed on the importance of engaging in meaningful occupations, occupational performance, and the wellbeing that arises from this (e.g., Stav et al., 2012; O’Sullivan and Hocking, 2013; Du Toit et al., 2018; Hammell, 2018; Tatzer, 2019; Zinger et al., 2020; Strick et al., 2021). This research adds to this existing knowledge by demonstrating the complexities of occupational engagement for people with dementia, and by identifying varying intensities of engagement to help therapists maximise the potential for wellbeing.

As is evident from the literature searches and research conducted in recent years, occupational engagement as a construct within occupational therapy practice remains ill-defined and open to interpretation. The other notable factor when reading research around occupational engagement is that the majority of the research has been conducted with people who are recovering from mental health conditions, such as schizophrenia. Indeed, the research carried out by Morris (2012) was centred around men within a secure psychiatric unit. This was also noted by Black et al. (2019), who commented that measures which seek to evaluate and quantify occupational engagement only appeared in studies within mental health, suggesting that this is an area with a greater emphasis on occupational engagement. This is significant in relation to this research: although dementia care is commonly positioned within mental health services, it could be argued that it is not a mental illness. The changes which occur in the brain are organic in nature, caused by a physical change to the structure of the brain, and are irreversible at this time. This means that those who are diagnosed with dementia are not in a state of recovery: they are in a position of decline, tasking the therapists who work with them to find ways to maintain function, adapt occupations, or seek to find alternate occupations which provide opportunities for engagement and positive outcomes which promote wellbeing. The proposed framework for occupational engagement arising from this research intends to provide greater depth of understanding the factors involved in attaining occupational engagement in addition to the elements of occupational engagement to assist therapists in helping people with dementia achieve a greater depth of positive engagement and more positive consequences so that wellbeing can be both realised and maintained.

The elements of the Occupation in Dementia Framework will now be discussed in relation to the six existing themes of occupational engagement in order to consolidate and validate the findings of this research.

15.1 Active Involvement in Occupation

This is described by Black et al. (2019) as “the active involvement, participation or performance of occupation”. For Morris (2012), this was the entry point to the Occupational Engagement Framework and is an essential element for occupational engagement to occur. This remains true in the Occupation in Dementia Framework: in order for there to be occupational engagement, there must first be an active participation in the occupation. The proposed framework also considers that there are factors to consider prior to this, in order for participation to occur. However, occupational engagement is more than active participation, and the proposed framework considers that there is a spectrum of engagement, ranging from negative to positive, which arises from the participation in an occupation.

15.2 Finding Value and Meaning

This is defined by Black et al. (2019) as engagement in occupations in which an individual found meaning, value or personal significance. For Morris (2012), the value was the key element, and it was the value of the occupation which gave rise to occupational engagement. For the Occupation in Dementia Framework, value remains significant. However, the value was found be related to whether the person participated in the occupation in addition to the occupational engagement. What was significant for people in this study was that they often were unable to participate or achieve the depth of engagement in valued occupations because of the nature of their cognitive impairment, with many valued occupations left behind. It is an important consideration for people with dementia as participation in valued or meaningful occupations may result in more negative occupational engagement if they are unable to achieve the consequences that they previously achieved, whilst newer occupations with no current personal value (because they are new occupations to the individual) may provide greater depth of positive engagement. This was also supported by the findings of Phinney et al. (2013) who found that the loss and absence felt by people with dementia in the absence of successful participation in valued occupations was devastating and had a profound effect on the future participation in occupations and the sense of self-identity.

15.3 Subjective Experience of Engagement

Black et al. (2019) found that many studies referred to the psychological, cognitive, and emotional effects of occupational engagement. Kennedy and Davis (2017) referred to interest, self-perceived efficacy, motivation, and feelings of choice as being integral to occupational engagement. For Morris (2012), this is linked with the value of the occupation (motivation and choice) and also the consequences of participation in the occupation. With the proposed framework, the subjective experience lies throughout. Motivation, interest, and choice are factors which influence whether a person chooses to participate in the occupation. If the individual is not motivated or interested, or the element of choice is removed, they may not participate in the occupation, and therefore occupational engagement is not achieved. In addition, there are personal consequences which arise from participation, and these may be more positive or negative according to the depth of engagement achieved whilst participating in the occupation. It is also proposed within this framework that the subjective experience resulting from participation in occupations (and the subsequent engagement achieved) influences future participation in occupations and can also affect the depth of engagement within an occupation.

15.4 Social and Environmental Interactions

Within their systematic review of the literature, Black et al. (2019) found that many studies referred to occupational engagement as occurring within social and environmental contexts, and that this was key to achieving occupational engagement. The proposed framework considers social and environmental factors as significant influences on the individual, which can promote or reduce opportunities for participation in occupations and can also affect the depth of occupational engagement (positive or negative). This is very much reflected in the work of Sixsmith et al. (1993) and Kitwood (1997) who promote the social and environmental support of people with dementia in order to maximise potential for participation in occupations. It was found within this research that appropriate support can facilitate participation in occupations and can also promote more positive occupational engagement, helping the person with dementia to achieve more positive consequences (and therefore a greater sense of wellbeing).

15.5 Balanced Engagement

In their findings, Black et al. (2019) found that balance in occupation was featured in many definitions of occupational engagement. Many arose from the definition provided by Bejerholm and Eklund (2007) who stated that a balance between occupations and also between occupation and rest was a critical element of occupational engagement. Craik et al. (2010) further described occupational engagement as participating in occupations in a balanced way. Morris (2012) also provided the element of balance within her description of occupational engagement, stating that a balance was required between positive and negative valued occupations in order to achieve wellbeing. Participation in more occupations with a negative value would create a sense of illbeing, whereas participation in more positively valued occupations would promote wellbeing. The element of balance is also considered as a factor in this research, however non-participation in valued occupations is also considered as a value. If a person with dementia has a greater number of valued occupations that they are unable to participate they are more likely to be experiencing illbeing. This is an important consideration for therapists: the imbalance should be corrected by encouraging or facilitating participation in occupations which can achieve a more positive engagement to counter the valued occupations which are no longer possible.

15.6 Occupational Deprivation

One of the factors that arose from the participants of this research was the effect of a lack of participation in valued occupations. In Occupational Science, this would be referred to a ‘occupational deprivation’. Occupational deprivation occurs when individuals are not able to participate in occupations which are meaningful, or which are necessary for overall wellbeing (Whiteford, 2010). For the participants of this research, this was twofold: some had been prevented from participating in occupations by others (e.g., family members) and some had stopped participating in valued occupations because they were no longer able to complete the tasks cognitively or physically or because they could no longer access them. Much of the research around occupational deprivation assumes that people with dementia have this imposed upon them because of the care they receive (e.g., Harvey, 2016; O’Sullivan and Hocking, 2013) which does not allow them to participate in meaningful occupations. However, participants of this research continued to participate, and achieve positively intense engagement, in occupations at the day centre, but continued to feel a sense of deprivation and loss at occupations that they were no longer able to participate in. For therapists, this creates a conundrum for people with dementia with the functional abilities of those within this research: we can provide access to and facilitate participation and positive engagement in occupations, but the sense of deprivation remains.

The use of the balance of occupations is well placed to help therapists to overcome occupational deprivation with people with dementia: if positive engagement with positive consequences can be achieved in a greater number of occupations than the individual has a sense of deprivation, we are more likely to achieve wellbeing. Interestingly, some of the participants chose not to participate in occupations which had been valued, even with support. Instead, they chose to experience new occupational challenges. This is also reflected in the work of Du Toit et al (2018), who noted that therapists need to explore opportunities for occupational engagement beyond the life history of the person with dementia to reduce limitations and increase opportunities for wellbeing.

15.7 Developing Identity Through Occupation

The notion of identity and occupation being intrinsically linked was highlighted by Black et al. (2019) as being present several studies, with occupational engagement presented as being able to create or influence identity. This was evident throughout this research, with many participants describing themselves by what they do or did throughout their lives. Several participants highlighted their own need to be 'doing' and not feeling idle or lazy, and the loss of identity that arose from being unable to participate in valued occupations was distressing. Some of the participants continued to participate and achieve positive engagement in some of their valued occupations, whilst others found that their engagement was less positive, and this had more negative consequences for them and impacted on their own identity. This is also supported by previous research which places occupation as central to supporting the identity of people with dementia (Tatzer, 2019; Kielsgaard et al., 2021: Strick et al., 2021).

15.8 Self and Occupational Engagement

The notion of self was considered throughout this research and was central to the design and methodology choice. The preservation of self is considered an essential part of good dementia care, as proposed by Kitwood (1997), and is important in achieving a sense of wellbeing for people with dementia. The notion of self is different to that of identity, although the two are intertwined. Identities are described as the elements which describe who you are: the traits, characteristics, social relations, roles, and social group memberships (Oyserman et al., 2012), whereas self is much more than this. For the purpose of this research, the term 'self' is used in relation to the term personhood (Kitwood, 1997) and selfhood (Sabat, 2001). Both of these definitions refer to the importance of our own notion of being who we are, and also who we are with others. The importance of occupational engagement and self was highlighted by participants throughout their interviews, but particularly by Sally, who commented that "Doing is life". Being able to continue to achieve occupational engagement was central to the sense of self for the participants, in being able to continue to experience life and be a valuable member of society. This is supported by the work of Blank et al. (2015), whose research demonstrated that occupational engagement was important existentially: without occupational engagement you don't exist. Jackman (2014) also stated that occupational engagement requires an investment of self and denotes being and presence. This is crucial for people with dementia, who may find that as their ability to participate and truly engage in occupations that have supported their sense of self throughout their lives are no longer accessible. This was perhaps most evident for Brian, who was experiencing feelings of depression and sadness that he was no longer able to participate in valued occupations which supported his sense of self. The importance of occupation was also discussed by O'Sullivan and Hocking (2013), who presented this within the scope of occupation giving purpose to life.

The Occupational Engagement Framework which was proposed by Morris (2012) did consider the person, however for the person with dementia who finds their abilities slowly eroding as a result of the illness, maintaining a sense of self is crucial. The Occupation in Dementia Framework encourages the therapist to consider this by looking at the factors affecting an individual, the value of occupations, the intensity of engagement (and whether this is positive or negative) and the consequences of this in order to promote more positive outcomes which will support the sense of self.

15.9 A Spectrum of Engagement

As previously discussed, the Occupational Engagement Framework proposed by Morris (2012) provided a range of values that could be assigned to occupations. Following this research, the range of values has been adapted to become a spectrum of occupational engagement, providing a range of increasingly negative or positive states of engagement. Jackman (2014) described occupational engagement as the manner in which an individual performs an occupation, i.e., the degree to which that person is involved in the task. The notion of a continuum of engagement has been discussed previously, suggesting that individuals can be more or less engaged in an occupation (Kennedy and Davis, 2017). Bejerholm and Eklund (2006) proposed a range of three modes of engagement: mostly disengaged, partly disengaged, and mostly engaged. Similarly, Sutton et al. (2012) identified four modes of engagement: disengagement, partial engagement, everyday engagement, and full engagement. The previously identified modes were a result of research with individuals who were recovering from mental illness, and referred to more global engagement in daily life.

The Occupational Engagement Framework proposed by Morris (2012) identified six values that could be assigned to an occupation: absorption, engagement, interest, indifference, disengagement, and repulsion. In that framework, occupational engagement was one of the values. Following this research, it is proposed that the values are actually different modes of engagement, in line with previous research into occupational engagement. However, engagement and disengagement were changed to involvement and disinvolvement. This expands the previous research to include new modes of engagement, which may allow a therapist to analyse occupational engagement in more depth. Furthermore, the proposed framework following this research is applicable to each individual occupation, recognising that people with dementia may be able to find a greater intensity of engagement in some occupations than others over the course of a short space of time. Whereas a person recovering from mental health difficulties may find that they are unable to achieve positive occupational engagement globally, a person with dementia may find this more occupation specific. It is anticipated that the proposed framework may help therapists to identify which occupations provide the greatest positive engagement, which provide negative engagement, and the effects of the consequences of participation for the individual in relation to future occupations.

15.10 Wellbeing from Occupational Engagement

The association between wellbeing and occupational engagement in people with dementia is very well documented (e.g., Hasselkus and Murray, 2007; Stav et al., 2012; O'Sullivan and Hocking, 2013; Hammell, 2017). Indeed, a whole approach to dementia care for occupational therapists has been created by Jackie Pool (2008), which seeks to identify occupations which provide the greatest wellbeing and to evaluate ways in which these can be supported by caregivers.

In the Occupational Engagement Framework, Morris (2012) proposes that those who participate in occupations which are engaging, and who achieve positive consequences as a result, are more likely to experience a sense of wellbeing. This is supported by Sutton et al. (2012), who found that for people recovering from mental illness, time spent in full occupational engagement experienced increased happiness and wellbeing. For the participants of this research, this was also true: a more positively intense engagement in an occupation which produced positive consequences provided a greater sense of wellbeing for individuals than those which did not. In addition to this, as previously discussed, occupational engagement can promote a sense of identity and support the sense of self which, in dementia care, is a crucial element for achieving a sense of wellbeing (Kitwood, 1997). This is intrinsically linked with the notion of balance within occupational engagement and is depicted by the image of the weighing scales both in the original Occupational Engagement Framework and in this research. In order to achieve the sense of wellbeing, a balance of occupations is required, with a greater number of occupations which provide positive engagement and positive consequences being crucial. For the people of this research, the balance of occupations must also consider valued occupations which the person can no longer participate, as a lack of balance in this respect causes greater illbeing.

15.11 Summary

The examination of more recent research and systematic reviews into the meaning of occupational engagement has provided support for the development of the new framework for people with dementia. This research further develops the understanding of occupational engagement for people with dementia, considering that recovery is unlikely and further deterioration in occupational engagement over time is probable. The proposed framework further the research into occupational engagement and provides a detailed structure for therapists to use when working with people with dementia in order to maximise opportunities for participation in occupations and to examine the intensity of engagement so that wellbeing can be achieved.

(Image Created by Peter)

16. Implications for the Occupation in Dementia Framework in Practice

Having reviewed the existing framework and proposed changes to this, it is now important to discuss how this might be used within Occupational Therapy practice within the field of dementia care. Occupational engagement is a very complex concept and differs from one individual to another. It is essential for wellbeing and consists of a number of intricate factors which determine the intensity of the engagement, whether this is positive or negative and the consequences that result.

As discussed in Chapter 2, occupation is essential for the health and wellbeing of people with dementia (as it is for all adults), but more so as the person faces challenges to their self-identity and increased occupational deprivation as their ability to engage in meaningful occupations diminishes (O’Sullivan and Hocking, 2013). This research supports the argument that positive occupational engagement can provide a sense of wellbeing to the person with dementia and allows the consideration of the complex factors described by O’Sullivan and Hocking (2013) which can result in occupational deprivation e.g., personal factors, social ecosystems and environmental issues which can prevent a person from participating in occupations and thereby prevents occupational engagement. In addition, using the framework within a therapeutic environment can help the therapist to understand which occupations are meaningful and provide the greatest occupational engagement. Applying the framework to people with dementia as they participate in occupations can provide an understanding of which occupations are valued, which provide more positive engagement, and which provide the most positive and successful consequences for that person. This in turn allows the therapist to focus on ways in which participation and engagement can be maximised by applying strategies to lessen any effects from personal factors, social ecosystems, and the environment.

The new framework allows the therapist to take a holistic view of the individual and not focussing only on the illness itself. This follows the principles of the person-centred dementia care model proposed by Kitwood (1997) and Brooker (2007). It encourages the therapist to view the person and the factors which influence them in relation to participation in occupation and achieving occupational engagement. For occupational engagement to occur, the therapist initially needs to consider the factors affecting participation. This includes knowledge of the person, their physical environment (or the environment of the occupation), and their social ecosystem. Once the therapist holds the knowledge of these elements, they can seek to minimise and disruption to participation in occupations (to achieve occupational engagement) and can put in place strategies to maximise participation.

Once the factors relating to the individual have been addressed, the occupation itself can be considered. This might involve adapting the occupation or providing strategies or equipment which would facilitate participation, it might involve choosing a different occupation, or it may require the therapist to consider what is meaningful to the individual.

Once all the elements for participation have been addressed and considered to enable or facilitate participation, occupational engagement can occur. As discussed, engagement varies in intensity for each individual and for each occupation, with some occupations promoting positively intense engagement, and others less so. In some cases, engagement may be negatively intense (this was observed during a Pets as Therapy session with Ethel, where she found the dog repulsive). As suggested by Morris (2012), occupations which promote more positive intensity are more likely to produce positive consequences and a greater sense of wellbeing for the individual.

Consequences are also an important consideration within occupational engagement. Whilst they are important for the individual in terms of future participation in occupations and general wellbeing, they also provide the therapist with feedback on the engagement and whether the considerations and adaptations prior to participation were effective. Positive consequences suggest that the conditions for participation and therefore engagement were supportive, whereas negative consequences would imply that conditions were not optimal, and the therapist needs to re-visit the individual and occupation elements of the framework again.

The whole process of the Occupational Engagement Framework is dynamic, and changes occur not only over time, as suggested by Morris (2012), but also within an occupation. The complex factors which exist within the framework can influence occupational engagement within an occupation over a short space of time. This was demonstrated in particular by Fran, who was affected by mood and her physical health whilst being observed at the centre, and both of which affected her occupational engagement.

The loss and absence experienced by people with dementia when they became unable to participate in occupations which once defined them has previously been identified as a significant influence on wellbeing (Phinney et al, 2013; Trahan and Carlson, 2014). This was true with many of the participants of this study, but especially Brian who described his sadness at being unable to participate in the occupations that defined him as a person. However, he found new occupations which provided him with positive consequences, helped him to re-define who he was. Many of the participants valued new learning and experiencing occupations that they had not previously participated in, and chose to not participate in previously valued occupations because they would be unable to achieve the engagement they had previously enjoyed because of the symptoms of dementia. Not only does this help to overcome some of the loss and absence felt, but the achievement of positive consequences helps to maintain and increase a sense of wellbeing. In addition, the finding of new valued occupations that can successfully achieve more positively intense occupational engagement and positive outcomes can support the personhood of the person with dementia. As discussed in Chapter 2 this is an important element of person-centred dementia care, and helps the person achieve a greater sense of wellbeing. Cohen-Mansfield (2019) described how it can be very difficult to identify occupations that replace those which have become less engaging or which the person can no longer participate in, however using the occupational engagement framework might help therapists achieve this. The use of the framework in this instance can help the therapist to understand why a person no longer participates in certain occupations and can help identify those which provide the maximum occupational engagement and the most positive consequences in order to support personhood and increase wellbeing.

Although new occupations were important to the participants of this study, not all past valued occupations were left behind, with some participants continuing to participate and finding positive engagement and consequences from this. What was apparent however, was that some grading of the occupation was necessary to compensate for their cognitive and physical losses. This is supported by Regier et al. (2017) who argued that appropriate grading of the occupation itself and appropriate support can enable a person with dementia to continue participating in valued occupations. The occupational engagement framework allows the therapist to thoroughly investigate the factors which affect participation and the challenges of the occupation itself so that appropriate support can be given, and grading applied to the occupation. An example of this was provided by Brian and his ability to perform on stage. Because of his physical difficulties and cognitive changes (person) he would find it difficult to perform as he previously did. In addition, he would find it very difficult to get onto the stage and stand whilst he performed (environment). However, he felt that with support from his fellow performers (social ecosystem), some adaptations to the stage environment, and in performing a song he was very familiar with (prism of occupation) he would be able to continue performing on stage.

Anecdotally, I have used the Occupational Engagement Framework in practice when working with people with dementia. Often caregivers continue to encourage the person to participate in occupations which previously held value, but which are now very difficult for that person to complete even with support. This causes much frustration for both the caregiver and the person with dementia and can lead to immense illbeing. Encouraging both parties to consider that whilst those occupations remain valued on a personal level, it is ok to leave them as such but to try other, perhaps new, occupations which provide an opportunity for occupational engagement and positive consequences. Similarly, encouraging caregivers to allow the person with dementia to leave behind the occupations which hold less value in place of spending time with more valued occupations can be valuable to achieve wellbeing. An example of this was a lady who found little value and positive consequence in carrying out her housework and cooking. She found a greater value, positive engagement, and consequences from going out on the bus on a daily basis to local towns, where she could take her time looking in the shops. In appraising this situation, it was agreed that formal carers would be employed to take care of the less valued occupations so that she had more time to enjoy those occupations which gave her greater engagement and more positive consequences. This resulted in a much greater sense of wellbeing for this lady, improving her physical and mental state.

It should be noted here that the usefulness of this framework has potential to extend beyond occupational therapists. Whilst the day centre used in this research does have input from an occupational therapist, many centres within the United Kingdom do not have access to occupational therapists, and activities are facilitated by skilled staff who do not hold a health qualification. In this instance, it is believed that staff could be trained to make use of the framework in order to help them plan and carry out activities which are relevant to an individual and which will provide the most positive consequences. In applying the framework to individuals attending the centre, staff may be able to identify occupations which will maximise participation and increase wellbeing, thus increasing the overall value of attending the day centre.

17. Entangled Lifeworlds: Reflections and Influences

As discussed in Chapter 5, it is essential for researchers to consider the ways in which their own previous knowledge and experiences shaped the research in order to maintain integrity and reliability within hermeneutic phenomenological research (Neubauer et al., 2019). In this chapter, I discuss some of the influences that I effected on the research. Furthermore, I place a lens on the ways in which the research has affected and changed me both personally and professionally.

17.1 Research Design

When considering this research, my own values, ideas, and previous knowledge influenced the very nature of the research from the start: the notion of person-centred dementia care and what this means both to me and to the participants was core to the choice of methodology and the methods used within the research. The reading completed around the notion of self in dementia and the phenomenological grounding of this helped to determine that for me, the design of the research should also follow a phenomenological approach. This allowed the investigation of occupational engagement with the participants and to understand their personal experiences. This is supported by Sparkes and Smith (2014), who argued that as researchers, we choose a particular paradigm because it supports our values and embodies the assumptions we hold about the world we inhabit. The decisions made throughout the research were all based on my own situational position within the systems I inhabit personally, professionally, and academically, which highlights the need for reflexivity to appreciate my own power and position within the research process (McNarry et al., 2018).

The choice of interviews as a method of data collection was also influenced by my own previous experience. As a therapist working within a dementia setting, I have developed excellent skills in being able to develop good relationships with others and in helping people with dementia share their experiences and feel at ease in doing so. This involves being a good listener, being sensitive and compassionate towards the participants, especially when sharing sensitive information, and using these skills to develop a relationship which is based on trust, honesty (Davis, 2020). Using interviews within this research utilised these skills so that the participants were given the opportunity to talk at length about their own situations comfortably. Many of the participants shared deeply personal experiences, and I believe that this was made possible because of the skills that I have developed in my practice as a therapist.

17.2 Researcher Versus Therapist

This is a complex issue for clinicians who are entering the world of research and was briefly discussed in Chapter 4 in relation to the selection of participants. The first instance of this was in my encounters with Fran: her conversations with me during the interviews were at times very emotional and she spoke about several topics which tugged at the therapist in me. The first of these was around her personal distress and the depth to which this ran. It was very difficult to remain impartial about this, and even more difficult to not transfer into therapist mode. During conversations I had to remain within the boundaries of researcher and had to raise the issues with staff at the centre who could discuss these further with her key worker. In particular, this was around her comments about her wish to die and also her relationship with her husband. Throughout the interviews, I tried to remain as a researcher and allow her to speak about her experiences and what this meant to her, and also to not become embroiled in her distress around her situation. She also brought concerns around the staff at the centre and the way they behaved towards her at times, and again it was difficult at times to remain impartial and just let her speak. This was also the case for Ethel, who was very distressed at times during her interviews. Again, I discussed my concerns with staff at the centre. During the discussions with staff at the centre, I was able to develop my understanding of Ethel and Fran, as the staff were able to provide historical accounts of their mental state and reassure me that any concerns would be dealt with, which allowed me to remain in the role of researcher without having to raise the concerns with others outside of the centre e.g., safeguarding, mental health key workers. Whilst the staff at the centre are not fellow researchers, it was useful to discuss some thoughts and experiences with the staff who could provide further opinions and reflections on the participants. Care was taken again to ‘bracket’ some of my own opinions when listening to these accounts, and also to ensure that the opinions of the staff did not influence my interpretation of the experiences of the participants.

17.3 The Self and Dementia

As shown in Appendix 1, a great deal of reading occurred around the notion of self and dementia. Whilst my previous studies had pivoted around person centred dementia care, in particular the approaches by Tom Kitwood and Steven Sabat in the 1990’s, I felt it crucial to investigate this further in order to be able to truly apply the approach to this research. I can honestly say that I was not anticipating the effect that this would have on me. One of the factors which prompted this reading was a quote from a carer of a person with dementia at an event I attended. He spoke about his wife responding to his statement of “Be at peace” with the following:

> *“I am not at peace; I am in pieces”*
>
> *(Khan and Khan, 2016)*

This notion of being fragmented and the sense of turmoil this brought led me to consider further what happens to the self when a person develops dementia and their memories of a whole lifetime become challenged. The reading that ensued was certainly emotional, and at times moved me to tears. It can honestly be said that this reading changed me and my approach to people with dementia on a deep level personally and professionally. The opinions of some schools of thought really challenged my values and beliefs around this and made me more determined than ever that the opinions and experiences of the participants of this research should be investigated and portrayed accurately in order to give them a voice that otherwise may not be heard. This was strengthened further during the interviews and conversations with the participants, who provided me with a lot of information about who they were and what was important to them, proving that they are not dementia…. they are a person. In particular, Fran and Brian gave strong arguments about how they were fighting dementia: they were doing all in their power to challenge the changes in their cognition to prove that they were still an individual with a life worth living.

17.4 Emotional Conversations

Some of the participants became very emotional during their interviews. In particular Fran, Brian and Ethel engaged in some difficult and emotive discussions which were challenging to hear. The topics were brought by the participants, and although not always pertinent to the topic of occupational engagement, they were listened to as these conversations were felt important not only to hear them as individuals, but also to increase the sense of who they were and the factors which were important to them at the time. Fran, Brian, and Ethel were all emotional at times, and cried when discussing certain elements of their lives, past and present. Again, this had an emotional impact on me which was unexpected. Fran was a younger lady, with interests that supported her self-identity. Being unable to participate in these was very challenging for her, and it certainly made me think about how it must feel to not be able to express yourself individually and the effect this must have on your sense of self and identity. Brian was a gentleman who very much reminded me of my father in terms of his values and previous occupations. When he cried because he was no longer able to participate in these occupations and described how this made him feel, it was almost heart-breaking because I could imagine my own father describing this. Similarly, Ethel described the loss of a much-loved husband and son, and how this loss affected her emotionally and occupationally. As a parent and wife, this loss seems almost too much to bear. Indeed, this had such an impact that when presenting this information, it reduced me to tears when trying to express the impact that dementia and the personal losses had on these individuals.

I was not expecting to have such an emotional response to the ‘data’, and yet here I was feeling such sadness. Identifying where the emotion was rooted and why helped me to place my own emotions and separate them from the research. Doing this helped me to ensure that I did not cloud the interpretation of the data from the interviews with my own perceptions of how the participants must be feeling, instead allowing me to focus on what was actually said and to relate this to the research topic. This highlights the importance of being aware of one’s own situatedness to the lifeworld of others – ensuring that the interpretation remains focussed on what the individual is describing, but also drawing on previous experiences and understandings in order to illuminate further the experiences of the participants (Heidegger, 1867; Neubauer et al., 2019).

17.5 Researcher Influences on Participants

Initially, I did not feel that I would have much influence over the participants: I was going in as a new face who had not met them before and was trying to recruit participants to a study. However, as the recruitment and research process progressed, it became apparent that I had influenced the participants, albeit positively. The first indication of this was when Brian told me that his wife had sent him off to the centre telling him that his “girlfriend” would be waiting for him (me!). Brian laughed whilst relaying this story, but it became apparent during the interviews that at times he was flirty in his interactions and also commented on how he did not recognise me one day because my hair was different. Whilst this may not seem significant on the surface of things, it may have influenced what he talked about, especially when talking about the person he used to be. That said, Brian did disclose some very personal information about his current situation, and the fact that he felt comfortable in my company undoubtedly encouraged him to talk about such difficult matters. In particular, he spoke about the difficulties he had with personal care and continence, are never easy topics to discuss with strangers. Many of the participants asked if they had answered my questions properly and had given me the information I was looking for at the end of the interviews. This demonstrates that they were hoping to be as helpful as possible and wanted to do their best to contribute to the research. Reassurances were always given that they absolutely had helped and provided very useful information, but this also demonstrates that they were keen to please. This undoubtedly resulted from the relationships that were built with them individually, but also may give rise to questions about whether this influenced the research. It is hoped that the open nature of the interviews and the limitation of direct questioning allowed the participants to elicit some control over what was discussed and therefore ensuring that the conversations were more natural in content rather than being controlled and requiring specific answers.

I was also aware that as a part of the information provided to the participants, they were informed of my background as an occupational therapist. This may have given me some power in the researcher/participant relationship, and may have influenced their willingness to participate in the research. Being aware of this potential power relationship meant that I could work hard to ensure that they did not see me as a therapist and more as a researcher looking to discover their own experiences and opinions. I was very careful not to cross the boundaries into being a therapist and at all times my intention was to treat all participants as important contributors to research into occupation and dementia, thus turning the power back onto them. Again, bracketing helped with this process, because I was able to ask participants what they meant by their statements during the interviews and ask about their experiences of occupations rather than making assumptions based on my own experiences.

17.6 Influences on Data Analysis

Davis (2020) describes the process of data analysis as a tripartite relationship between the data, the researcher, and the participants. That is, the data is generated by the participants and then the transcripts are filtered by the researcher using their own personal philosophy which is informed by their own values, attitudes, and previous experiences (Davis, 2020). In this research, the participants provided me with their own views and experiences which were then transcribed and analysed. The process of analysis was conducted using the framework proposed by Morris (2012) initially, but later developed further according to the details provided by the participants. This was then further filtered based on my own philosophy, which is founded in years of practice as a therapist and previous research (both my own and that of others). This allowed me to focus on what was required in terms of the development of a new approach to occupational engagement for people with dementia, and prevented me from becoming overwhelmed with data which relates to other elements of the experiences of people with dementia. This was particularly important, as the participants discussed a lot of different elements of life and how this has been impacted by not only dementia but also the ageing process and failing physical health. Applying this filter allowed the focus to remain on occupational engagement whilst continuing to allow the experiences of each participant shine through to allow the co-construction of new knowledge.

17.7 Summary

This chapter summarises some of the factors which influenced this research. Although I attempted to ‘bracket’, or set aside, my own values, beliefs, and preconceived ideas, it is clear that these were integral to the research from the point of design through to analysis of the data. The process of reflexivity allowed me to acknowledge these factors and in doing so the awareness of these influences allowed the data analysis to be more authentic and true to the participants. The most surprising outcome of the process of this research and the reflexivity was not the influences that I imposed upon the research, but the effects that the research had on me: as a researcher, a professional and also a person. The privilege of working with the participants and the information they shared was overwhelming at times, and the deeper reading that ensued as a part of the process, allowed me access to a much deeper awareness and understanding of the lived experience of people with dementia and to develop a framework based on this. This is very much in keeping with the hermeneutic circle discussed in Chapter 5, whereby being absorbed in the data and engaging with previous and new knowledge helps to construct a deeper understanding of the lived experience of others. In the case of many of the participants of this research, the lived experience was at times extremely positive and determined but at other times distressing and fraught with sadness and loss. Most importantly, this has increased my own desire to ensure that people with dementia are given a voice and are heard, not only in research but also in practice and everyday life.

18. Unique Contribution to Knowledge

This research has investigated the application of the Occupational Engagement Framework developed by Morris (2012) to people with dementia in a day care setting. Whilst some elements of the framework were indeed applicable, the findings from the data analysis suggested the development of a new framework which would seek to provide therapists with a tool to examine the occupational engagement of people with dementia so that greater outcomes can be achieved.

Examination of the currently available research identified that there is a lack of consistent information about occupational engagement and how this might look for people with dementia. Through the examination and interpretation of the themes arising from the data, the Occupation in Dementia Framework was developed. This framework addresses the issues arising from the lived experiences of the participants of this research and, using the applicable elements from the Occupational Engagement Framework, presents the factors which should be considered by therapists when examining the occupational engagement of people with dementia, specifically within a day care setting. The Occupation in Dementia Framework encourages the therapist to examine personal and occupational factors which might promote or inhibit the individual in participating in occupations. Furthermore, the framework provides a spectrum of intensities of engagement which allow the therapist to closely examine participation in an occupation so that overall engagement can be maximised to increase a sense of wellbeing.

This research also identifies the importance of valued occupations in relation to supporting the self or personhood of a person with dementia and encourages therapists to evaluate occupations in order to support self-identity. The importance of meaningful occupations is well documented in research, however the Occupation in Dementia Framework positions valued occupations at the core. These are occupations which support the self of the person with dementia and are considered of greater importance than those which hold meaning.

This research also identifies that new learning is important to people with dementia, especially in circumstances where they are no longer able to participate in valued occupations or engagement in these is less positive (with less positive consequences). When this occurs, exposure to new occupations can help the person with dementia to find value in new occupations which support self and promote wellbeing, replacing the loss of those which can no longer be accessed.

The Occupational Engagement Framework proposed by Morris (2012) also considers the effect of participation in occupation on overall wellbeing, and states that a balance of occupations is required to achieve this. This research also found this, but also highlighted that the consideration of valued occupations which can no longer be participated in must be considered. If a person has many valued occupations which are no longer accessible, and these are not replaced or made achievable, this contributes to an overall sense of illbeing. This further emphasises the importance for therapists to consider the occupational balance for people with dementia, ensuring that they can participate in, and achieve positive intensity engagement from, valued occupations. The Occupation in Dementia Framework is designed to help therapists in this process so that all the elements of participation in occupation can be addressed to maximise the potential for participation and engagement.

This research consolidates previous findings and theories about occupational engagement and the importance of participation in occupation for people with dementia. Building on this, the findings of this research have resulted in the formulation of a framework which draws together many of the elements of previous knowledge in this area and incorporates the experiences of the people within this research. The Occupation in Dementia Framework is designed to be an accessible tool for therapists to use in a day care setting to examine the occupational experience of people with dementia to maximise the support for self-identity and wellbeing through occupation.

19. Recommendations for Future Research

Following this research, it is understood that further research would be beneficial to determine if the outcomes and proposed framework are applicable to other groups. Whilst this research is applicable to the participants (i.e., people with dementia who attend a day service), it would be useful for further research to determine if the same was true for people with dementia who are participating in occupations outside of a day centre environment. Whilst occupations not at the centre were considered, for many of the participants, opportunities to participate in occupations away from the centre were limited because of their personal situations, cognitive abilities, and physical difficulties. It would be useful to know if the findings of this research were applicable to people with dementia who are maintaining a high level of function within their usual home environment and within their own social networks (which may mean the recruitment of individuals who are in the early stages of the disease).

Conversely, it would also be helpful to conduct research with people with dementia who have been living with dementia for some time and who need a much higher level of support to participate in occupations than those who were involved in this research. This would require further ethical consideration as it is more likely that those individuals would have difficulties with capacity and therefore may have issues in providing informed consent.

It is also noted that the demographics of this research were limited, with all participants being white British. Further research including participants from different ethnic backgrounds would be useful in developing an understanding of occupational engagement from a different perspective.

It is also recommended for further research to develop a measure of occupational engagement that would allow therapists to clearly evaluate occupations and the intensity of engagement achieved. For this research, an observation form was created using the work of Morris (2012), and this provided a good checklist to evaluate what was being observed against the framework. Further research could establish whether this checklist was applicable for therapists in practice, or whether it should be developed further to clearly assess the intensity of engagement for individuals during an occupation. The development of such a tool would complement checklists such as those used within the Pool Activity Level Instrument (Pool, 2012) and the Bradford Well-being Profile (Bradford Dementia Group, 2008) in helping to encourage people with dementia in achieving a sense of wellbeing, allowing them to live well with dementia.

Furthermore, future research in the application of the Occupational Engagement Framework (Morris, 2012) to other areas of practice within occupational therapy would be beneficial to establish if the adaptations to the framework proposed here are relevant to other health conditions or just dementia. As previously discussed, dementia care is a more unique dimension of occupational therapy as recovery is not the aim of therapy, and deterioration is inevitable. Further research would help to establish if the original framework was best suited to therapy which is recovery focussed.

19.1 Dissemination

Following the completion of this research it is important to consider how the findings will be disseminated to others to ensure that the experiences of the participants are shared and can influence future dementia care. Table 2 below highlights some of the plans for dissemination. Over the course of this research, three papers were published based on the additional reading completed. These are detailed in Table 2 and are also included in appendices 1-3. The purpose of these articles was to raise awareness of the self in dementia, the construct of dementia and also the challenges that are faced when completing research with people with dementia.

Table 2: Dissemination plan

Area of interest	***Dissemination plan***
Dementia and self	*Published in 2016:* *Hampson, C. and Morris, K. (2016) Dementia: Sustaining Self in the Face of Cognitive Decline. Geriatrics, 1, 25*
The construct of dementia	*Published in 2017:* *Hampson, C. and Morris, K. (2017) Dementia: Normal Ageing, Political Cause or Social Construction? Open Access Journal of Gerontology and Geriatric Medicine, 1(4)*
Ethical and methodological challenges to research into the experiences of a person with dementia	*Published in 2018:* *Hampson, C. and Morris, K. (2018) Research into the Experience of Dementia: Methodological and Ethical Challenges. Journal of Social Sciences and Humanities, 1(1): 15-19.*
Research question, process, results, and conclusion	*Plans for publication in a journal e.g., Journal of Occupational Science*
The importance of occupation in dementia	*Plans for publication of the summary of literature searches and research outcomes to highlight the importance of occupation for people with dementia e.g., Journal of Dementia Care (a journal read by professionals, people with dementia and carers of people with dementia).*
Expansion of the Occupation in Dementia Framework in practice	*Dissemination via presentations (work-based, conferences) to raise awareness of the framework.* *Development of a manual which could be used within day care settings by staff (qualified and unqualified). This may require application for further funding to be able to complete further evaluation of the framework in practice and to develop a user-friendly manual which is accessible to all who work in dementia care settings.*

Future dissemination will focus on sharing the outcomes of this research. This will be shared via journals which are relevant to occupational therapists. In addition, it is felt that sharing the outcomes of the literature searches and research in relation to the importance of occupation in dementia would be beneficial. In this instance, it is felt that this would be useful to people with dementia, their caregivers and also the professionals who work with them. For this purpose, the Journal of Dementia Care will be approached. This is a journal which is read by people with dementia and their caregivers as well as professionals.

Further development of the Occupation in Dementia Framework is also planned in order to expand this from a theoretical framework into one which is accessible to those working with people with dementia, in particular in a day care setting. For this purpose, further applications for funding will be required in order to further evaluate the framework in practice and to develop a manual that can be used by qualified and unqualified staff within a day care setting to maximise the occupational engagement of people with dementia.

20. Conclusions

This thesis has examined the application of the Occupational Engagement Framework to people with dementia in a day care setting. Through applying a hermeneutic phenomenological approach, the experiences of people with dementia were obtained through interviews and observations. Using thematic analysis, themes were identified from the data to examine whether the Occupational Engagement Framework was applicable to the participants, based on their experiences at the time of the research. It was found that whilst the Occupational Engagement Framework had some relevant application, the experiences of the participants were not truly reflected and a new framework, the Occupation in Dementia Framework, was developed. This framework places value in a new position within the framework, situating it within the confines of occupation, and not the participation/engagement. In addition, the overall positioning of occupational engagement as a value within a set of values was challenged, with participants describing positive and negative engagement in occupations. It was deemed that for the participants of this research, engagement was a spectrum with occupations resulting in more positive or more negative engagement. In addition to this, it was found that the factors influencing the person were crucial to the participation in occupations. This is important for therapists to consider because these factors can encourage or inhibit participation in occupations, and therapists may be able to facilitate a change in these factors to allow the individual more opportunities for participation in valued occupations. In addition, it was found that the consequences of participation in occupation were influential on participation in future occupations and also within an occupation. The ability of an individual to participate in valued occupations and achieve more positive consequences was found to be essential for the wellbeing of the individuals and also important for self-identity.

In addition to the development of a new framework for therapists to use in practice when working with people with dementia in a day care setting, there are several important points for consideration. One of the most important themes from the participants was that of the value of occupation. Much of the identified research refers to meaningful or purposeful occupations. However, this research positions important occupations as being of value to the individual. These are more than meaningful, purposeful occupations: participants identified that occupations support their sense of self. The importance of self in people with dementia is well documented, and participants identified that occupations were often a reflection of their self-identity. When they were no longer able to participate in the valued occupations which supported the self, their sense of wellbeing decreased. Participants identified that they were more likely to participate, and experience a more positive intensity of engagement, in occupations which supported their sense of self. Interestingly, participants reported that new occupations which supported new learning were important and they allowed the continued support of self, using their current skills and abilities. These occupations provided more positive consequences and a greater sense of wellbeing for the participants. The participants also described the importance of occupation, stating that “doing is life” and is essential to prevent them from feeling lazy or idle, thus providing them with purpose and adding meaning to their lives.

The development of the new framework is a useful tool for therapists working with people with dementia. A review of previous literature confirmed the relevance of each of the elements of the framework, and consolidated the experiences of the participants to that identified by other people with dementia during previous research. The framework amalgamates and develops previous knowledge on the occupational engagement of people with dementia, identifying the personal and occupational factors which influence participation and providing a spectrum of intensities of engagement. These factors can help therapists to identify any inhibiting or supporting influences on the person with dementia so that they can help the individual to overcome any difficulties so that they may experience more positive engagement and therefore greater consequences. The awareness of the spectrum of engagement and the resulting consequences can also help therapists to identify occupations which provide more positive consequences. In addition, the therapist can begin to identify consequences which may influence in-the-moment engagement in the occupation, allowing the therapist to grade and adapt occupations accordingly to facilitate a better outcome (i.e., more positive consequences). The overall purpose of the framework is to help therapists explore influences on participation and engagement in occupations so that an increased sense of wellbeing can be achieved. This is particularly important for people with dementia as the decreased participation and engagement in valued occupations can lead to a sense of illbeing, and this was indeed described by participants of this research.

In conclusion, this research defines a new framework for therapists to apply to people with dementia in a day setting, so that appropriate occupations can be offered. The framework helps to identify factors which may influence the participation and engagement in occupations, so that the best possible outcomes can be achieved. This helps therapists to ensure that occupations are valued, and reduces the assumptions made when consequences are less positive and there is a reluctance to participate. In doing so, the therapist can lessen the effects of personal and occupational factors so that maximum positive intensity is achieved, thus helping to support the self-identity of the individual and create a greater sense of wellbeing overall.

Appendices

Appendix 1: Sustaining Self in the Face of Dementia

geriatrics

MDPI

Discussion

Dementia: Sustaining Self in the Face of Cognitive Decline

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Abstract: It is argued that the way in which we view a person with dementia can have a significant effect on the level of disability and wellbeing of the person. There is a divergence between a belief that the self disintegrates, leaving a non-person, and a belief that the self remains but is misplaced and can be maintained with the appropriate approach from others. This article seeks to examine the differing approaches to self and personhood in dementia care, and establish ways of approaching care for the person with dementia which may limit the extent of disability in the face of cognitive decline.

Keywords: dementia; self; personhood; phenomenology

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1. Introduction

Over the last 20 years, social psychology has become very prominent in the area of dementia care; proposing a notion of personhood which places the person with dementia at the centre of care, challenging and advancing alternatives to the understandings of dementia that were focussed on decay, decline and deficiency [1–3]. This alternative viewpoint on dementia is not a new one however, and has its background in phenomenology and the idea of 'self'. This philosophical approach seeks to identify the "subtle and profound ways person–body–others–world are intimately *intertwined*" [4].

However, within the notion of 'personhood' there are two distinct opinions of the self and dementia that have arisen within the field of phenomenology. This article seeks to explore these opposing viewpoints and establish the most relevant position for healthcare professionals working in the field of dementia care.

2. Missing Person: Have You Seen Her?

> "Her body might be with us, but her soul has left the room". [5]

The above quote is from a song by Rick Guard (released in 2012 to raise funds for the Alzheimer's Society). The song is written about his mother, in which he describes her as a "missing person". The song is a very moving and personal account of his experience with dementia, and interestingly describes a particular view of personhood held by Heidegger (1889–1976). This viewpoint is one which considers the human existence to be self-interpreting, with a temporal understanding of being and a dynamic engagement with the world through our bodies [6]. When a person has dementia, the cognitive dysfunction erodes our "being-in-the world" [6], which splinters the sense of being and therefore the sense of self. It is argued that the process of being in the world is disrupted, new experiences cannot be retained, and eventually the physical aspect of experiencing the world is impaired as cognition declines [6]. This approach to dementia considers that the person is undergoing a loss of self, which results in a non-person [7]. Indeed, Davis [6] states that dementia is:

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> "....a fraying of the self. Dementia effects the dismantling of the self until there is nothing left." [6]

This position assumes that the decline and loss of cognitive functions (e.g. consciousness, rationality, intentionality, memory, reciprocity, communication), causes a disintegration of personhood and an unbecoming of self [8–12]. If we adopt this standpoint and view people with dementia as a non-person, the ethical requirement to provide care and support is diminished [13]. This reduces care input so that only the physical needs of the person are met, and also risks that the life of the person is seen as meaningless [13,14]. Indeed, Singer [15,16] argues that a person with dementia gradually becomes and "empty husk" and that beyond a certain stage, the person is gone. He goes on to argue that a person with dementia should be euthanised in order to reduce the economic burden and the burden on caregivers [15,16]. However Singer's utilitarian perspective has been heavily criticised, with some saying that Singer is 'dangerous', an intellectual psychopath, a 'Nazi' and morally wrong [17–19].

Herskovits [11], argued that this approach to the self in dementia stemmed from the medical model approach to care, and was nurtured to meet the needs of researchers, research institutions, and to solve clinical, practical and psychological issues. She argues that the discourse around the loss of self in dementia has created a vision of the person with dementia as a "dehumanised monster", which generates a fear of growing older as people try to face their own "future potential monstrousness" should they develop dementia (p. 160, [11]).

From a practitioner perspective the perception that the self is eroded to nothing as dementia progresses is very difficult to accept, not least because people in the later stages of the illness are often still able to interact on a basic level with their environment, and are therefore demonstrating an ability to be in the world. Millett [7] argues that people with dementia continue to exist in the world of others (as parents, siblings, spouses, etc.), and therefore continue to have a value as a being. The cognitive losses do not make them of any less importance, and therefore an alternative view of the self in dementia should be sought. Interestingly, Herskovits [11] pointed out that this approach to the self in dementia is cognitively focussed, i.e. the self is inextricably linked to cognition, therefore any deterioration in cognitive ability leads to a diminishing of the self. This is different to other models of self in dementia care which were proposed towards the end of the nineteenth century, such as those proposed by Kitwood [20], Sabat and Harré [21] and Robertson [22] which place the focus on other factors for influencing the self and personhood on the person with dementia.

3. A Misplaced Being

> "I am not at peace......I am in pieces". [23]

The above statement is from a lady with dementia. It is her response to being told to be at peace, and describes how a person with dementia experiences a fragmentation of self, rather than a loss of self [23]. While a very poignant statement, it also serves to demonstrate an alternative view of the self in dementia through bio-phenomenology, as described by Jakob von Uexküll [24]. This was a view held by Husserl, Scheler and Merleau-Ponty, and recognises that in spite of degenerating cognitive abilities the person with dementia continues to experience the world and create meaning, often in affective responses to stimuli e.g. laughing, crying, expressing frustration [7]. Indeed, it has been shown that in people with severe amnesia that an affective response may continue even after the memory of what instigated it has gone [25]. This is supported by the symbolic interactionist view that the self is concealed rather than lost as the dementia progresses [13]. This viewpoint allows carers of people with dementia to provide care beyond the basic physical needs of a person, bestowing meaning to their lives and enriching their daily experience [13].

Ashworth and Ashworth [26] further this notion by stating that we should consider the person as a whole i.e. the person with dementia AND the illness itself in equal measures. They suggest that the person with dementia continues to have a changing inner-life, and that their bodies continue to carry out actions without conscious control (i.e., pre-reflexively) even in the later stages of the illness. This implies that we need to acknowledge the disease process, and that this changes people (therefore not assuming that people stay the same) and how they interact with the world, while at the same time appreciating that the person with dementia is an embodied being who can interact on varying levels with their world even if this is on a pre-reflexive level.

Cohen-Mansfield et al. [27] stated that the sense of *personal self* continues throughout the process of cognitive loss in dementia, even though many other personal and social identities diminish. This is echoed by more recent research into identity of the person with dementia. Caddell and Clare [28] found that the self was dichotomous: some elements of self remained as dementia progressed while other elements changed through the course of the illness, which caused those diagnosed with dementia to feel in a state of flux. This has important connotations for care of people with dementia in that the care giver must be sensitive to the individual's past and present identity, being mindful of any changes to this so that appropriate support can be offered.

4. Personhood

Taking forward this notion of 'self', a more contemporary concept of 'personhood' has been developed within dementia care. The notion of personhood is not new, and was originally discussed by Rene Descartes (1596–1650) and John Lock (1632–1704). The original perspective was based on the idea that cognition (e.g. the ability to remember past events and actions, self-identity and reason) is essential for personhood to exist [29]. While not a new idea, this altered approach of personhood within dementia care was introduced by Tom Kitwood in the early 1990s as a new way of understanding dementia and providing support in order to maintain personhood [8]. This reconceptualisation of personhood follows a social constructionist approach. That is, personhood is defined as "a standing or status that is bestowed upon one human being by others in the context of particular social relationships and institutional arrangements" [30]. This perspective of personhood promotes a shift from the biomedical model, suggesting that the symptoms (i.e. performance, behaviour) and quality of life of the person with dementia are a result of the social interactions of the person with others rather than a result of the neurological changes [31].

Sabat also proposed an alternative view of the self within dementia following the social constructionist view. He proposed that the self has 3 forms: self 1, the singular self; self 2, the physical, mental and emotional characteristics of a person and the beliefs they hold about that; self 3, the publicly presented persona [21,32–34]. Sabat stated that the self in all of its forms exist through engagement with others, and that this relies on the cooperation of others within a social context to construct the identity of a person [21]. When a person has dementia, their collaborative attempts to create a particular self with another person may not be successful if the other person refuses to cooperate. This, according to positioning theory, places the person with dementia in a negative position, which can cause misinterpretation and social misunderstandings of their behaviour [21,35]. In terms of dementia care, the social positioning of the person with dementia is important: if negatively positioned, the self of the person is deconstructed to the point of being lost. If the person with dementia is positively positioned and supported, the self is maintained.

Kitwood developed an approach to dementia care which sought to view personhood in social terms, suggesting that the approach of carers was essential to supporting the self of the person with dementia [2,36]. He described the ways in which the actions of caregivers (intentional or unintentional) can have a detrimental effect on the wellbeing of a person with dementia [3]. Kitwood called these negative interactions 'Malignant Social Psychology' and he went on to describe 17 types of interaction (or 'Personal Detractions') which range in severity and cause a reduction in wellbeing in the person with dementia [2,3,37]. Indeed, Tom Kitwood went on to describe the process of 'rementia' which can happen when the personhood of the person with dementia is supported [38]. This approach to the person with dementia can create the phenomenon of temporary improvement or stabilisation in the symptoms of dementia [38]. It has been argued that rementia occurs when changes are made to the personal, social and neurological influences on a person with dementia, and that supporting a person in this way can lead to them regaining some of their lost abilities [20,37–41].

While Kitwood's approach to dementia care has been widely adopted throughout services, it is not without criticism. Some argue that the approach does not go far enough to encapsulate all of the factors which apply to people with dementia, including citizenship, embodiment, discourse, and spirituality [8,42–44]. Additionally, more recent research has suggested that personhood is transient according to the situation of person with dementia, and that people with dementia often strive to retain their sense of personhood in spite of the diagnosis of dementia [45,46]. Indeed, one author went so far as to say they found no evidence of a loss of personhood in people with early stage dementia and supportive caregivers, with little evidence of Kitwood's 'malignant social psychology' and participants who maintained a positive sense of self even after living with dementia for some time [46]. It was acknowledged in this study that those involved had good support networks which potentially preserved the sense of self in the person with dementia. This would imply that Kitwood's theory of person centred care was correct and that with the correct support a person with dementia can maintain a sense of personhood.

5. Embodied Selfhood

Of the criticisms of Kitwood's notion of personhood, the concept of the embodiment of self is particularly pertinent to the care of a person with dementia. This was proposed by Pia Kontos following a period of research in a specialist Alzheimer's unit within a Canadian long-term care facility. Kontos proposed that selfhood is not only the consequence of social interactions with others, but it is also the unique way in which our bodies reflexively behave to express our individuality [42]. This was derived from the works of Merleau-Ponty [47] and Bourdieu [48], who argue that our bodies act habitually and pre-reflexively (i.e. without cognitive awareness) to interact with the world. Kontos argued therefore, that people with dementia act in a pre-reflexive manner to express their selves and interact with others, and that this is manifested in the way their body moves [42]. It is argued that embodied selfhood should be made central to the care of a person with dementia, and the intricacies and subtleties of behaviour and action embraced [42]. In doing so, a greater understanding of the ways in which people with dementia remain connected with others through the projection of their selves through non-verbal means would be developed [42].

6. Conclusions

While the approaches to the self in dementia discussed here are not exhaustive, they represent the current mainstream opinions within dementia care settings within the UK. Historically, the view that the self erodes to nothing or a non-person was the predominant approach, directing care which was not person centred. However, since the advent of the approach proposed by Tom Kitwood, the view has changed to one which recognises that the self and personhood of a person remains and must be supported in order to increase the wellbeing of a person with dementia. Kitwood's Person-Centred Model of Dementia care has proved to be excellent in advancing the care of people with dementia, however, this is not without flaws, and other approaches should be considered which progress this approach to create supportive, inclusive and understanding care for the person with dementia.

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Appendix 2: Dementia: Normal Ageing, Political Cause or Social Construction?

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Dementia: Normal Ageing, Political Cause or Social Construction?

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Abstract

Dementia is an increasing issue in modern society. Advances in medicine and technology have provided greater detail about the physiological causes of dementia, and awareness of the illness is becoming more widespread throughout wider society as governments attempt to find a way to manage the challenges the illness brings. But is dementia an illness in its own right, or is it part of a continuum of brain deterioration that happens naturally as we age? And how does the current medical, political and social stance influence the care of people with dementia? This article briefly examines the various opinions on these matters with a view to raising awareness of the influences on public opinion of dementia and the care people who experience this illness receive.

Keywords: Dementia; Political; Social; Economic; Medicalisation

Introduction

Medical advances since the time of Alois Alzheimer have allowed us to understand the symptoms and causes of Alzheimer's Disease and other dementias from a physiological perspective. With advances in medical science around autopsy work, imaging techniques, and in obtaining evidence of symptomology from people with dementia, we now understand much more about the different types of dementia. However, is the cognitive decline caused by dementia different from normal ageing, or is it the end of a spectrum of degeneration? The following communication examines opinions regarding the 'medicalisation' of dementia, and how this influences political courses, policy development and the wider views of society.

The ageing brain continuum...?

Brayne and Calloway [1] argued that there is little research to suggest that dementia of the Alzheimer's type is anything other than a continuum of changes in cognition as the brain ages. This is more recently supported by Deary et al. [2], who state that the age related cognitive decline forms a continuum, and the point at which a person is deemed to have pathological cognitive impairment can change. Similarly, Davis [3] argues that the identification of the pathological changes in brain tissue which help the medical world to identify dementia do not consider that the act of ageing itself is indeed pathological i.e. our bodily tissue degenerates as we age. Armstrong [4] states that the degenerative changes that occur across our bodily systems in the ageing process create a disparity around what is 'normal' and what is pathological, i.e. are the pathological changes in fact normal?.

There has been much research in age-related cognitive decline [5-8] suggest that there is a functional disconnection which occurs as we age, caused by age-related anatomical and biochemical changes that occur within the white matter of the brain. But when do these changes begin? Salthouse [8] concluded that age-related cognitive decline starts once maturity has been reached, although others disagree [9-12]. Interestingly, cognitive decline is not found to be global, and accumulated knowledge e.g. vocabulary and general information, continues to increase until around age 60 [2,8,13,14].

However, Caccappolo-van Vliet et al. [7] describe differences between normal ageing, preclinical dementia and Alzheimer's disease. They state that often the symptoms of Alzheimer 's disease are often mistaken for 'normal ageing', and that the deficits of preclinical dementia are very similar to those experienced in age-related cognitive decline.

While it should be acknowledged that there are arguments for dementia being part of a normal cognitive decline continuum and also for it being a pathological condition which is more prevalent in those over age 65, Medina [15] tates that it can be difficult and problematic to draw a definitive line between illness and normality. The variables for establishing these arguments are vast (e.g. neurological changes, education, previous testing, general health and wellbeing) and difficult to control in order to establish a definite answer [2,6,8,16,17].

A political conundrum

Regardless of whether dementia is part of a continuum or a disease in itself, there is little doubt that the issue of cognitive decline is one of great importance to the population. The biomedical advances in the knowledge of dementia has served to create a fear of the illness within the general public [15]. Loss of memory is one of the most feared parts of growing old, and the care of people with cognitive impairment places great financial, societal and personal difficulties on the population [2]. Indeed, the growth in an older population (and therefore growth in the number of people with dementia) has very much become a political issue on a national and global scale. World Health Organisation [18] estimate that 47 million people worldwide currently have dementia, and that this will increase to 75.6 million by 2030, which has led the world leaders to collaborate in the quest for finding a 'cure' for dementia and increasing the research in this area to find ways of reducing the burden on society.

In 2013, the word's first G8 summit on dementia was held. This was a gathering of ministers from the G8 countries, researchers, pharmaceutical companies and charities, who all met to discuss ways in which they can invest in dementia research, improve the preventions and treatments available for dementia, and improve the quality of life for people with dementia [19]. Prior to this, in 2012, David Cameron (UK Prime Minister), produced the "Prime Minister's challenge in dementia". This is a "challenge to the whole of society as well as government" (p.5) to improve care for people with dementia by improving health and care, the creation of dementia friendly communities, and improving research in the area of dementia care [20]. Indeed, there has been much policy around dementia care in the past 7 years [21], which has very much led to the issue of dementia being at the forefront of many campaigns, perhaps being the "most publicised health problem in old age" [22]. More recently, older adults, in particular those with dementia, have been portrayed as a burden on society's resources in terms of care provision and financial means. The 2017 UK election saw the main political parties debate the cost of dementia to society and argue how best to manage the financial burden to the country.

Innes [23] suggests that the politicising of dementia has its origins in the economic issues of dementia care. Indeed, the economic cost of providing care for a person with dementia is huge across a population, reported to be in excess of £26billion per year in the UK alone [24,25]. Perhaps the first issue sought by a government is that of data collection, i.e. how many people have dementia, which leads to the estimated cost of providing care for those people [23]. This, along with the discovery of drug treatments which claim to slow the illness down, leads to a crusade to achieving early diagnosis which will provide information on how many people live with dementia and will allow more people to access cost-effective drug therapies, preventing the need for more costly interventions later on [26].

Alternatively, the politicisation of dementia can be seen as a way of the government controlling the population. Katz [27] argued that the government attempt to constrain a population by monitoring it because they see it as a threat to stability of the "economic, moral and political orders" (p.23). Davis [12] argues that this creates an element of power for the government, which allows them to produce a more appealing view of old age: by creating a view that dementia is not an inevitable part of ageing, and through the promotion of research to find a cure/treatments, the ageing population can feel more reassured that they may 'escape' dementia. Harris [28] argues that this serves to appease an ageing population, who otherwise would be facing dementia as a 'normal' part of ageing.

However, the political focus on dementia is not all bad. The prominent political lens on dementia has piqued the interest of policy makers and research funder holders to search for a cure and place the needs of people with dementia and their carers at the centre of social policy [15]. Longley and Warner [29] also suggest that in addition to the economic issues raised by such an increase in numbers of people with dementia, the politicisation of dementia also gives rise to a spotlight on a more humanitarian view of dementia: changing the focus to the person with dementia, the maintenance of the self and personhood of the person with dementia. This is perhaps the most important element to the issue, and should be at the forefront of all interactions with a person with dementia, as it can help to shape the way society views dementia.

The social impact on dementia

In addition to the medical and political constructions of dementia, we should also consider the impact of the wider society on the issue of dementia, in terms of the impact on the person with dementia and the general held opinions on the term 'dementia'. Indeed, the way in which society sees dementia can determine whether the image is comforting or one which causes a sense of dread [3,30,31], and this can have a huge impact on the way in which a person with dementia views himself and the illness, and the way in which they receive care [31]. The literature in this area describes how the medical and political views of dementia are inextricably linked [3,30], and how they can influence the wider society's image and viewpoint on dementia.

Davis [3] describes how the medicalisation of dementia has served to place dementia in the public view as a biomedical

disease, rather than a normal part of ageing, which has served to problematic dementia. Harding and Palfrey [32] suggest that in spite of this, the Western view of dementia places it as an illness of old age, and therefore creates a sense of fear in an ageing population.

Clare [31] describes how cognitive skills, independent function and the ability to contribute to the economy carry a high importance in western society. This is therefore challenged when a person is diagnosed with dementia: people with degenerative cognitive impairments become unable to function independently and can no longer contribute economically, which greatly affects their status in society.

The views held by the family and wider social network of the person with dementia are also important. Often, they may be influenced by personal experiences of dementia (e.g. grandparents who had dementia), or may have been prejudiced by the views of others about dementia (e.g. their parents may have referred to people with dementia as "gaga" or "mad") [31]. Similarly, the person who is experiencing dementia may hold views of the illness, which can place them in a negative social situation. The views of the wider society can also be influenced by representations of dementia in the media (e.g. documentaries, T.V. drama, films, advertising campaigns). The way people with dementia are projected by such means not only informs, educates, increases and consolidates awareness of dementia, but it also has the ability to influence how wider society responds to, understands and perceives the illness [15,33].

Interestingly, Adams [30] discusses a change in legislation and policy which attempts to change the approach to people with dementia and their carers, so that caregivers are recognised as important in their role, and that the needs and wishes of both the carer and the person with dementia are recognised in care provision. Indeed, this is particularly so in the publication of the National Dementia Strategy [21]. However, Innes [23] stated that while social science is attempting to change the view of dementia, it is difficult to infiltrate mainstream opinion and change the care that people receive.

Conclusion

In summary, we can see that the medical, political and social position on dementia has a large impact on how dementia is perceived by individuals who are facing the illness, either as a relative/caregiver or as a person who is experiencing cognitive impairment. Some may argue that dementia is a normal part of ageing which is being medicalised and used as a political and economic cause. However, there can be no doubt that the increased understanding about the causes and symptoms of dementia, the political agenda to reduce the economic burden of dementia, and changes in policy around the care people with dementia and their carers receive is working towards reducing the stigma of dementia and increasing awareness of the support that people with dementia require. Hopefully, this will lead to a reduction in the disability caused by dementia and enable those affected to live well in spite of their cognitive impairment.

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Appendix 3: Research into the Experiences of Dementia: Methodological and Ethical Challenges

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Research into the Experience of Dementia: Methodological and Ethical Challenges

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Abstract: Conducting research in the field of dementia care can be fraught with moral and ethical dilemmas, particularly with regard to consent and capacity. These issues apply to all aspects of the research process and are an important consideration for the research to be considered ethical and of relevance to the future of dementia care. This article considers the importance of ethical issues in research involving people with dementia, with specific regard to consent and capacity and on minimising harm. Methodological suggestions are proposed which may assist in ensuring research is ethical and maximise participation of people with dementia. In conclusion, it is argued that consideration of these factors at a methodological level can increase the potential for engagement without compromising the wellbeing, dignity and protection of the person with dementia.

Keywords: Ethics, Dementia, Methodology, Research

1. Introduction

In recent years, there has been a shift in research within the field of dementia. Historically, the person with dementia was not included in the research process, and the research was done 'to' them, rather than 'with' them [1, 2]. This predominantly relates to the traditional ideation that a person with dementia had lost their 'self' and was no longer able to contribute to society (and equally the research process) [3]. However, this approach marginalised the person with dementia, and the dawn of the reconceptualised person centred models of dementia care has resulted in a shift in research methods which are now more inclusive of the person with dementia.

Research involving people with dementia provides a valuable insight into the lived experience of dementia, deepening knowledge of the illness and enabling the development of care practices in the field of dementia care [4, 5, 6, 7]. It provides valuable information on the perspectives and experiences of the people affected by dementia, broadening understanding of the illness from the more historical research which centred on the clinical effects of dementia and the impact of caring for a person with dementia on caregivers [8, 9, 7]. Figure 1 summarises the key benefits of including people with dementia in the research process. However, there are many factors which need to be considered in order to protect the person with dementia and ensure that research is safe and ethical. These issues are complex, and consideration of these factors above and beyond the standard ethical requirements is required for research with people with dementia to be successful.

Figure 1. *The benefits of involving people with dementia in research.*

2. Capacity and Consent

The issue of capacity and consent is huge within the realm of dementia research, and this causes many obstacles for researchers to overcome in order to ensure that consent is obtained ethically and in order to protect the person with dementia. Consent is perhaps the most important aspect of research with anybody, not just people with dementia. This establishes whether the person actually wants to participate in the research [10]. There have been many debates and changes around the issue of consent over the past 20 years, but more recently a pattern is emerging whereby people with dementia are involved in the consent process to ensure that they are well informed and happy to proceed and continue in the study [6, 7, 11].

Informed consent is an essential element of most research with human participants (unless research is essentially covert), and is required for research to be ethically and legally compliant [12, 13]. The purpose of informed consent is primarily to ensure that the participants haven't been coerced or deceived into participating in the study, and to ensure safeguards are in place to protect those involved in the study [12, 13, 14]. Consent must be given freely and voluntarily, without influence or duress from others (e.g. researcher, health professional, family, friends), and must be given on the basis of the participants having received, understood, considered and agreed to the conditions of the study and the future implications of the research [13, 14]. Consent is often defined as the written agreement of an individual to participate in a research study [15], however considering the nature of dementia other methods of recording the consent may be required. Consent can only be truly classed as informed when the potential participant is able to understand the information presented to them and comprehend the implications of participating in the study [16].

One of the main concerns around the issue of consent is whether the person with dementia has capacity to give consent. Capacity is a legal term which is linked with the ability of an individual to understand information, make choices and communicate those choices to others [16]. All adults are presumed to have capacity until our ability to participate in society and make decisions regarding our welfare or property is called into question [17]. Capacity is described as a "dimensional quality of a person", i.e. it is measurable in the same way as blood pressure, weight and body mass index, and is considered a "precious component of personhood" [18, 19 p. 94]. The decisional capacity of a person is on a continuum of abilities: understanding (i.e. understanding the information regarding a research project); appreciation (i.e. recognising how the information relates to the person it applies to); reasoning (i.e. comparing options and understanding the consequences of the choices made); choice (i.e. expressing the choices made consistently) [20, 21, 22, 18].

When a person has dementia, in particular Alzheimer's Disease, they not only experience cognitive and functional impairment, but also experience losses in terms of their ability to make decisions (i.e. decisional capacity) [18]. While the person with dementia may be able to express an interest in participating in research, the nature of the illness means that their ability to understand and appreciate the consequences of being involved in the study is impaired [16]. The limitations of the person's cognition increases the vulnerability and risk of exploitation of the person with dementia, which means that researchers must take extra care in ensuring that the person with dementia is engaged in the consent process and that all efforts have been made to ensure that they have understood what the study is about and what participation means in order to maintain their human rights and ensure research is ethical [23, 16]. While the person with dementia may have some limitations to their decision-making ability, they should not be excluded from research because of this. Hougham [24] states that many people with dementia are capable of engaging in what he calls 'consent discussions', and that people with mild cognitive impairment are able to make consent decisions which are equivocal to persons without neurological impairment [25].

2.1. The Importance of Information Presentation

One of the ways in which consent can be maximised is by ensuring that the information provided is appropriate for those who will read it. The Medical Research Council (MRC) [12] states that it is important that researchers consider how to present their information to potential participants, ensuring that the lifestyle, interests, needs, religious beliefs and priorities of that person are respected. The MRC also advocates the use of creative and resourceful methods of gaining consent when potential participants have difficulty understanding more traditional means of information about the study and are communicating their consent [12]. This is echoed by McKeown et al [6], who state that people with dementia are more able to make decisions around participating in research when a relevant approach is used. This is an important concept to consider when recruiting participants with dementia, as they may have capacity to consent but may have difficulty reading, processing and understanding large amounts of written information, and may have difficulty with reasoning, making judgements and communicating their decision [26]. In such circumstances, it may be necessary to present information in a different way that can be more easily understood e.g. pictorially, verbally. This is supported by the Health Research Authority (HRA), who state that information provided should be appropriate to the person's capacity of understanding [14]. An important consideration for the presentation of information is that of the language used. Primarily, any communication with a person with dementia should be accessible, simple and presented in layman's terms, avoiding abbreviations and acronyms [27].

2.2. Ongoing Consent

When including people with dementia in research, it is widely recommended that consent is an ongoing process [e.g. 5, 12, 28, 6]. Several terms are used for this process i.e. ongoing consent, process consent, ongoing negotiated consent, continuous consent, but the philosophy is the same: consent is a process which happens throughout the research project to ensure that the person with dementia remains informed of the principles of the research and is happy to continue to be involved. This process is one of "continual renegotiations" and is used to determine whether participants are happy to remain in the research [29 p. 38, 26]. This is especially important when working with people with a memory deficit who may forget what the project is about and who may feel differently about the project as time passes because of further cognitive impairment/deterioration.

2.3. Negotiated Consent

Another method of gaining appropriate consent where capacity is limited is that of negotiated consent [30, 31]. Grout [31] argues that this method is a more progressive method of obtaining consent from people regardless of their age, disability or fluctuations in capacity, and it allows researchers to regard people with dementia as people with a valid and real view of their world. This approach recognises that people with impaired capacity may choose to share or defer the decision-making around whether to participate in research with another person of their choice (e.g. a spouse or descendent, health care professional) [31]. This approach eliminates the need for a proxy in situations where the person with dementia has limited capacity to consent, ensuring that they were involved in the decision over whether to consent to participate or not. Negotiated consent can be used to provide a person with an advocate in helping them make a decision and can be helpful in making those with limited capacity feel empowered [31].

2.4. Assent and Dissent

While consent is an important and necessary element for research to meet ethical requirements, researchers should also consider the notion of 'assent' when carrying out research, particularly when the participants may have difficulty in providing informed consent. Including the notion of assent/dissent in the process of research into dementia allows the person with dementia to express their own intentions regarding the research, and supports the personhood of participants who may otherwise be experiencing a diminishing choices and self-esteem in other areas of their lives [19]. Kim [32] states that the issues of consent within dementia research reinforce the need to consider assent and lack of dissent in conducting research with people with dementia, and that this should be an important ethical requirement.

Dissent is defined as "verbal or non-verbal indication of unwillingness to participate in study procedures" [33 p. 81]. The ways in which people may indicate that they do not wish to proceed vary according to the level of cognitive impairment they are experiencing, and while some may be able to verbally state that they do not wish to continue, others may express this behaviourally e.g. by being uncooperative, showing signs of agitation, trying to leave, or emotionally e.g. by becoming distressed or unhappy [33]. Researchers should look for signs of dissent at all times during contacts with participants. A relationship built between the researcher, the participant and their carer should allow the researcher to develop knowledge of the person with dementia and how they communicate, which will help to identify any moments of dissent and will ensure that the research has a good ethical grounding.

Batchelor-Aselage et al. [34] proposed The Partnership of Consent Protocol, a method for establishing consent, assent and dissent. This protocol includes the person with dementia and their legal representatives (i.e. court-approved guardian, health care agent, spouse, adult children, parents, adult siblings, aunt, uncle, other adult kin) in the decision-making around consent for the research. It also involves the legal representatives and gatekeepers in the process of gaining assent and recognising dissent, outlining a clear pathway to follow if dissent is noted. This protocol focuses on the process of consent, assent and dissent as being one of partnership between the person with dementia, their legal representatives and the researcher.

3. Minimising Harm

When carrying out research, it is essential that safeguards are put into place to prevent harm to the participants. This is particularly important when the participants have any kind of cognitive impairment which could affect their decisional capacity. The factors discussed here are not exhaustive, and are considerations additional to the usual ethical safeguards in human research.

3.1. Accidental Diagnosis Disclosure

One of the most significant factors which can cause harm in dementia research is the issue of accidental diagnosis disclosure [23, 7, 2]. This occurs where the researcher inadvertently informs the person of their diagnosis, and is an issue which can cause significant distress. This may occur because the person was unaware of their diagnosis (i.e. has never been informed), has forgotten their diagnosis, or may be because the person has never had an assessment for diagnosis. This can happen through the researcher using the words 'Alzheimer's' or 'dementia', or could even occur through discussing the symptoms of memory loss (a common symptom of dementia is loss of insight, which may mean that the person is not aware that they have a memory problem).

Pratt [23] suggests 5 ways of reducing the risk of accidental disclosure of diagnosis:

i. Checking with key people (e.g. gatekeepers, carers) about the person's understanding and knowledge of their diagnosis.
ii. Not mentioning the diagnosis until the person does.
iii. Finding 'safe' ways of discussing the symptoms the person experiences.

iv. Prioritising safety above informed consent by taking measures to avoid accidental disclosure of diagnosis
v. Informing key people of the research protocols

Pratt [23] suggests that the researcher allows the participant to instigate discussions around the symptoms of memory loss, and focuses on abilities rather than deficits during interviews by enquiring about feelings and experiences rather than facts. This will help to alleviate any feelings of distress which may be caused by asking the person to recall events/information which may not be accessible to them because of the cognitive impairment [23].

3.2. Unnecessary Reminders of Forgetfulness

As discussed by Pratt [23], asking a person with dementia to remember things may cause distress. As damage to the hippocampus in dementia causes the person to have difficulty in storing new information, this then makes it difficult for the person to recall events. In an interview situation, asking a person to recall something specific may cause them to feel under pressure and may cause them to experience distress. Pratt [23] suggests that the researcher should find creative methods to help the person discuss a topic which does not rely solely on their memory.

3.3. Taking Time

Pratt and Wilkinson [35] explain that people with dementia can vary in their performance from day to day (commonly described as 'good' and 'bad' days), may experience changes in their cognitive function over periods of time, and may take longer to feel safe enough to disclose information to researchers than participants without cognitive deficits. It is argued that spending longer periods of time with participants with dementia e.g. having several contacts over a period of time, not rushing interviews, has several benefits for the researcher and person with dementia [35]:

i. allows the researcher to observe and understand the context that the person operates within
ii. allows greater opportunity for understanding the person with dementia and their perspectives
iii. provides the researcher with greater opportunity to interpret meaning from interviews
iv. helps to build a rapport between the researcher and the person with dementia
v. reduces stress for the person with dementia as they are allowing them time to express themselves without rushing them

3.4. Re-living Upsetting Events

Participants may find that certain topics and questions in interviews evoke memories which are distressing and may encroach on unresolved issues [36, 37]. This may be particularly relevant because people with dementia often experience a different reality to the one others around them experience, meaning that seemingly innocuous questions can evoke unexpected memories for a person. In this instance, it is important to remain aware of the participant's behaviour and presentation during the interview, being mindful that distress can be shown in different ways and not just at the time of interview [38, 37].

4. Conclusion

Careful planning and attention to methodological issues around minimising harm and maximising opportunities for gaining consent can increase the potential for people with dementia to participate in dementia research. Involving people with dementia in the research process has many benefits, not least because it validates the personhood of the person with dementia and can help to reduce the stigma attached to the illness by illustrating that they are able to express their experiences, thoughts, feelings and opinions, regardless of their diagnosis. Failing to include people with dementia in research reinforces the negative stereotypes about dementia, particularly those around the belief that with a diagnosis of dementia brings incapacity and invalid experiences of life. Research which is inclusive of people with dementia challenges these stereotypes, and can help to change the ideology of society as a whole and encourages researchers and care providers to value the experiences of people with dementia.

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Appendix 4: Ethics Approval Letter

2 June 2017

Our Ref: DC/SB 16/69

Research Office
University of Cumbria
Lancaster Campus
Lancaster, LA1 3JD

Tel: 01524 384175
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Caroline Hampson
HPSS
Fusehill Street

Dear Caroline

Request for Ethical Clearance – Our Ref 16/69
Project: Applying the occupational Engagement Framework to people with memory difficulties

Thank you for your application for ethical review the panel members felt that this was an excellent application. There are no ethical issues, the panel have identified a number of enhancements for you to consider.

1. Consider the participants being able to review the paper/conference slides once you've written it up it may be they choose not to, but any areas where their photos are used I think it's important they see how exactly.
2. Consider adding in a debrief sheet
3. Obtaining consent - It is stated that '*The staff at the centre will be asked to help in nominating people'* but this appears to be a potential bias in selection. Need to clarify how, following engagement with staff at the day centres and applying the criteria for selection, the participants will be recruited
4. PIS - States that '*am testing this theory on people who may have difficulties with their memory who attend this day centre'* - suggest that the word *'testing'* is changed as it could be viewed as rather threatening and limit recruitment.

Approval is granted for the study.

With regards

[redacted]

Chair
Research Ethics Panel

Appendix 5: Blank Observation form

Value	Indicators	Tick	Observations
Absorption	Engrossed		
	Swallowed up		
	Entirely occupied		
	Enthusiasm		
	High level concentration		
Engagement	Commitment		
	Attachment		
	Entangled		
	Involved		
	Concentration		
	Pleasure		
	Enjoyment		
	Social engagement		
	Sense of achievement		
Interest	Curiosity		
	Concern		
	?Fun		
Participati	Takes part		
	Ambivalence		
Indifference	Disinterest		
	Unconcerned		
	Boredom		
	Poor motivation		
Disengagement	Uncommitted		
	Detached		
	Annoyance		
	Displeasure		
Re	Disgusted		

	Repressed Resisted Aversion Strong negative language

Appendix 6: Completed Observation Forms

OBSERVATION FORM

ID: Participant 1 Activity: Making Christmas Cake

Level	Indicators	Tick	Observations
Absorption	Engrossed		Was really involved with support from staff – weighing and mixing the ingredients. Stated that she was really enjoying the activity.
	Swallowed up		
	Entirely occupied	X	
	Enthusiasm	X	
	High level concentration	X	
Engagement	Commitment	X	Very involved in the activity. Chatting and smiling. Later became more social involvement and interest as physical engagement stopped.
	Attachment	X	
	Entangled	X	
	Involved	X	
	Concentration	X	
	Pleasure	X	
	Enjoyment	X	
	Social engagement	X	
	Sense of achievement	X	
Interest	Curiosity	X	Later engagement became more social and cognitive as she began to have pain. This stopped the intense physical involvement she had previously had to more social engagement
	Concern	X	
	?Fun	X	
Participation	Takes part	X	
	Ambivalence		
Indifference	Disinterest		
	Unconcerned		
	Boredom		
	Poor motivation		
Disengagement	Uncommitted		
	Detached		
	Annoyance		
	Displeasure		
Repulsion	Disgusted		
	Repressed		
	Resisted		
	Aversion		
	Strong negative language		

OBSERVATION FORM

ID: Participant 3 Activity: Sewing (making an apron)

Level	Indicators	Tick	Observations
Absorption	Engrossed		
	Swallowed up		
	Entirely occupied		
	Enthusiasm		
	High level concentration		
Engagement	Commitment	X	Was very involved in the activity, however she didn't display any signs of pleasure or enjoyment. Made noises while she was concentrating (like a humming noise)
	Attachment	X	
	Entangled		
	Involved		
	Concentration	X	
	Pleasure		
	Enjoyment		
	Social engagement		
	Sense of achievement	X	
Interest	Curiosity	X	Asked questions on what to do next/how to do the steps
	Concern		
	?Fun		
Participation	Takes part	X	At times, she sat uninvolved
	Ambivalence	X	
Indifference	Disinterest		
	Unconcerned		
	Boredom		
	Poor motivation		
Disengagement	Uncommitted		Although this was reported by the participant as a valued activity and something that has previously been enjoyed, she stated she did not enjoy the activity today because she "did not feel well"
	Detached	X	
	Annoyance		
	Displeasure		
Repulsion	Disgusted		
	Repressed		
	Resisted		
	Aversion		
	Strong negative language		

OBSERVATION FORM

ID: Participant 5 Activity: Reminiscence

Level	Indicators	Tick	Observations
Absorption	Engrossed		
	Swallowed up		
	Entirely occupied		
	Enthusiasm		
	High level concentration		
Engagement	Commitment		
	Attachment		
	Entangled		
	Involved		
	Concentration		
	Pleasure		
	Enjoyment		
	Social engagement		
	Sense of achievement		
Interest	Curiosity		
	Concern		
	?Fun		
Participati	Takes part		
	Ambivalence		
Indifference	Disinterest		
	Unconcerned		
	Boredom		
	Poor motivation		
Disengagement	Uncommitted		
	Detached		
	Annoyance		
	Displeasure		
Repulsion	Disgusted	x	Sat with her eyes closed for
	Repressed	x	much of the session, although

	Resisted Aversion Strong negative language	x x	she was listening and responding to questions. Negative comments made and did not wish to contribute to discussions.

OBSERVATION FORM

ID: Participant 6 Activity: Cooking

Level	Indicators	Tick	Observations
Absorption	Engrossed		Went into the kitchen and cooked the chilli that the group had prepared. Stood at the hob and stirred/cooked. Concentrated only on the task.
	Swallowed up		
	Entirely occupied	X	
	Enthusiasm	X	
	High level concentration	X	
Engagement	Commitment	X	Was really involved in preparing and cooking the food. Chatted with others at times Enjoyed tasting the food.
	Attachment	X	
	Entangled	X	
	Involved	X	
	Concentration	X	
	Pleasure	X	
	Enjoyment	X	
	Social engagement	X	
	Sense of achievement	X	
Interest	Curiosity		
	Concern	X	
	?Fun		
Participation	Takes part	X	
	Ambivalence		
Indifference	Disinterest		
	Unconcerned		
	Boredom		
	Poor motivation		
Disengagement	Uncommitted		
	Detached		
	Annoyance		
	Displeasure		
Repulsion	Disgusted		
	Repressed		
	Resisted		
	Aversion		
	Strong negative language		

Appendix 7: Information sheet and Consent form

Informed Consent Form for

This informed consent form is for people attending Charnley Fold day centre who wish to participate in the “Applying the Occupational Engagement Framework to People with Memory Difficulties” study.

Principle Investigator: Caroline Hampson

Name of Organization: University of Cumbria

Name of Supervisor: Karen Morris

Name of Project: Applying the Occupational Engagement Framework to People with Memory Difficulties

This Informed Consent Form has two parts:

- **Information Sheet (gives you information about the study)**
- **Certificate of Consent (this is where you sign if you agree to participate)**

You will be given a copy of the full Informed Consent Form

<u>Part I: Information Sheet</u>

Introduction

My name is Caroline Hampson. I am an occupational therapist and a Doctoral researcher at the University of Cumbria. I have worked with people who have difficulty with their memory for about 16 years trying to help people live well with memory loss.

I am going to give you information and invite you to be part of a research study. You can choose whether you want to participate.

You can talk about the information in this leaflet with anyone you feel comfortable talking to. You can decide on whether to participate or not after you have talked it over. You do not have to decide now.

There may be some words that you don’t understand or things that you want me to explain more about because you are interested or concerned. Please ask me to stop at any time and I will take the time to explain.

Why am I doing this research?

I am trying to understand how people with memory difficulties take part in activities and how this affects overall wellbeing. To do this, I am evaluating a theory called the “Occupational Engagement Framework” to find out if it applies to people with memory problems.

Why are you asking me?

I am evaluating this theory with people who may have difficulties with their memory who attend this day centre.

Do I have to do this?

You do not have to take part in this research. If you decide that you don’t want to be in the research it is OK and nothing will change for you at the day centre or anywhere else because of this decision. Even if you agree to join in now, you can change your mind at any point.

Do you know that you do not have to take part in this research study, if you do not wish to? Do you have any questions? If so, write them here so we can talk about them:

I have checked with ______________________________ and they understand that involvement is voluntary _____(initial)

What is going to happen to me?

If you wish to join in with this project, I will come to the day centre to watch you doing different activities. I will take photographs and make notes whilst watching you. The notes I take will help me to remember what I saw later in the project. The photographs will help me to remember what I saw. They will also help me to remind you of the activity later in the day.

Later in the day we will have a conversation about the activity and how you felt about it. I will ask you to look at the photographs of yourself and describe to me how you felt about the activity. The photographs will be used to help you remember what you were doing. I will record the conversations so that I can listen to them again and write them down. You will not be named in any written information.

I will visit you in the day centre several times to help me get a better understanding of the activities you like and dislike, and how this affects your day.

I will ask you at each point if you are happy to carry on being involved. You are free to stop at any point in the project. If you want to stop there will be no change to how you are treated at the day centre.

I have checked with ________________________________ and they understand what will happen ________(initial)

Do you have any other questions? Do you want me to go through what will happen again?

Is this bad or dangerous for me?

There should be no ill-effects from being involved in this study. Any information you give me will be treated confidentially. However, if you say something that worries me, I will alert the relevant agency for your safety. All information (for example notes, photographs, recordings) will be kept securely according to data protection laws, and will be deleted 7 years after the study has finished. Your name will not be on any information so that other people reading the results will not know who you are.

If you have any questions or concerns about anything to do with the study, you can contact me at any time to discuss them.

Do you have any questions or concerns about the risks of being involved in the study? Write them here so we can talk about them:

I have checked with ____________________ and they understand the risks and discomforts _____(initial)

Is there anything good that happens to me?

There may not be anything good that happens to you from joining in this study. However, it is hoped that the study will help occupational therapists to have a greater understanding of the importance of how people engage in activities.

I have checked with ______________________ and they understand the benefits_____ (initial)

Do you have any questions about how the study might help people in the future? Write them here so we can talk about it later:

Is everybody going to know about this?

I will not tell other people that you are in this research and I won't share personal information about you to anyone.

Information about you that will be collected from the research will be put away and no-one but the researchers will be able to see it. Any information about you will have a pretend name on it instead of your name. Only the researchers will know what your number is and we will keep that information secure. It will not be shared with or given to anyone.

The transcripts from the interviews and the photographs of you will be presented in my final thesis, but your name will not be present. Quotes from your interviews may be used in publications and presentations relating to the study, but no-one will know your name. Only photographs which do not show your face will be used in publications and presentations.

Did you understand the procedures that I will be using to make sure that any information collected about you will remain confidential? Do you have any questions about them? Write them here so that we can talk about them later:

Sharing the Findings:

The findings from the study will be shared with others, most likely through presentations and publications. Confidential information will remain confidential.

Do you understand that the findings from the study will be shared with others? If you have any questions about this write them here so that we can talk about it later. Would you like me to visit you to tell you what the findings were?

Who can I talk to or ask questions to?

You can ask me questions now or later. I have written a number and address where you can reach me. If you want to talk to someone else, for example a relative, friend or member of staff at the day centre, that is fine too.

Caroline Hampson (Main researcher)
Telephone: [redacted]
Address: Graduate Office
University of Cumbria
Room 9
Gressingham Building
Bowerham Road
Lancaster
LA1 3JD

Karen Morris (Supervisor)
Telephone: [redacted]
Address: Department of Health, Psychology and Social Studies
University of Cumbria
Fusehill Street
Carlisle
CA1 2HH

Do you know that you do not have to take part in this study if you do not wish to? You can say "No" if you wish to? Do you know that you can ask me questions later, if you wish to? Do you know how to contact me if you need to? If you have any questions, please write them here so that we can talk about them later:

You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Summary

The study is investigating how people with memory loss take part in activities.

I am asking people who attend this day centre to join the study.

You do not have to join – it is voluntary.

I will watch you carrying out activities.

I will make notes and take photographs of you doing the activity.

Later, I will talk to you about the activity. This conversation will be recorded.

I do not expect anything bad to happen to you if you join the study.

No-one will know that you are involved – I will change any information which might identify you.

The results will be shared in publications and presentations.

You can ask questions about the study at any time.

You can leave the study at any time.

All information collected will be kept safe.

Applying the Occupational Engagement Framework to People with Memory Difficulties

Participant Consent Form

Please read the following and sign if you agree:

Please tick:

☐ The purpose of the study has been explained to me

☐ I know I can ask questions about this

☐ I know that if I become uncomfortable, or don’t want to keep going I can stop at any time

☐ I know that the interview will be recorded

☐ I know that my name won’t be used but that things I say might be used

☐ I know that my photograph will be taken and that this will be used in the final written project only

Name of participant:____

Signature of participant: .... **Date:** ....

Copy provided to the participant ________ (initialled by researcher/assistant)

This consent form will be kept and stored by the person who you return this form to.

If you choose to be part of this research, I will also give you a copy of this paper to keep for yourself. You can ask your carer/relative to look after it if you want.

Appendix 8: Gatekeeper Information Sheet

Information Sheet for the 'Evaluation of the Occupational Engagement Framework" Study

Information for third parties

Principle Investigator: Caroline Hampson

Name of Organization: University of Cumbria

Name of Supervisor: Karen Morris

Name of Project: The Evaluation of the Occupational Engagement Framework

My name is Caroline Hampson. I am an occupational therapist and a PhD student at the University of Cumbria. I have worked with people who have difficulty with their memory for about 16 years trying to help people live well with memory loss.

I am trying to understand how people with memory difficulties take part in activities and how this affects overall wellbeing. To do this, I am testing a theory called the "Occupational Engagement Framework" to find out if it applies to people with memory problems.

I am testing this theory on people who may have difficulties with their memory.

What does the research entail?

In this study, I will be watching people with memory loss symptoms participating in different activities at the day centre. I will be taking notes and photographs of the person carrying out the activity which will help me to recall what I saw. The photographs will help to understand the person's participation in the activity, but will also provide a memory prompt and discussion point for the participant. Later in the day, I will carry out an interview with the participant to talk about their participation in the activities observed. This will help to form a story about the importance of activity to the person, and will help me to understand the value and consequences of participating (or not participating) in activities. The photographs will be used to help the person to remember what they did, and deepen discussions about the importance of the activity to the person.

What will I need to do?

The idea is that this project will not take up much of your time. I do not want to burden you with extra work. I may need your help to identify people who would be suitable for the project. I hope that we can create a partnership which to create new knowledge to help understand how people with dementia engage in activities.

Issues around consent

Participants will be provided with an information sheet, and will be given plenty of opportunity to discuss any concerns or questions they have about the research. They will be asked to sign a consent form; however, they will be asked at every contact if they agree to participate in the study. This will ensure that they are given opportunity to ask further questions and are able to remove themselves from the study or any part of it at any time. I will also be taking care to notice any signs which might indicate that the person is not happy participating, and will ensure that this is checked with the participant and yourselves to make sure that the person is happy to proceed or whether they wish to withdraw from the research.

Protection of participants

There should be no risk of significant harm from this study, however plans are in place to protect against issues which may arise. These include:

<u>Accidental disclosure of diagnosis</u> – I am fully aware that not all people with memory loss have, or are aware of, their diagnosis. Great care will be taken

not to discuss the term dementia unless this is discussed directly by the participant

Unnecessary reminders of forgetfulness – every effort will be taken to reduce the potential distress caused by asking people to remember events. This includes conducting interviews shortly after the activity has taken place, using photographs to prompt memory, and the termination of interviews if distress is shown.

Reducing stress – to reduce any potential for stress caused by the research, I will endeavour to spend time with the participants prior to the research starting to allow them to become familiar with me and to learn about any variations in their abilities over the course of a day. This will allow the person to become more familiar with me, and will allow me to be flexible according to each person’s individual requirements.

Re-living upsetting events – should the person experience distress during the activity, for example if they become upset, agitated or unhappy, photographs will not be taken. Similarly, if the person shows signs of distress during interviews about this activity (or any other activity or subject), they will be gently guided onto another, less distressing topic. If the distress continues, the interview will be terminated.

Maintaining dignity – the dignity of participants will be considered always, and if any images are capture which compromise the dignity of others, these will not be included in the research data.

Confidentiality

Every effort will be taken to ensure the confidentiality of participants. This includes changing the names of participants, day centre names, and names of staff and relatives mentioned in any interviews. Images of people who are not participants will be blacked out, and all identifying features of the venue e.g. signs.

All data collected will be transferred and stored onto a secure passworded system as soon as possible after the interviews and photographs were recorded/taken.

Exclusions to confidentiality and anonymity

If, during the research, a participant, carer, or member of staff at the day centre discloses important information which relates to the safety of either the participant or another person, I will seek further advice from the local safeguarding team. This may lead to disclosure with staff at the day centre, NHS staff, police, and/or Social Services, following safeguarding procedures.

Representation

Images gathered in the process of this research will not be broadly shared without prior consent from the participant. Data gained in the interviews will be carefully analysed and the interpretations checked with a more experienced researcher to ensure that the risk of misrepresentation is low.

Ownership

Copies of photographs produced during the research will be offered to participants to establish the shared ownership of the images. If a person withdraws from the study before it is complete, they will be asked for permission to use the photographs as data and will be asked if they consent to them being used in the final thesis.

Thank you for taking the time to read this leaflet. If you have any questions please do not hesitate to contact me:

Caroline Hampson (Main researcher)
Telephone:
Address: Graduate Office
University of Cumbria
Room 9
Gressingham Building
Bowerham Road

Lancaster
LA1 3JD

Appendix 9: Invitation Letter

Graduate Office
University of Cumbria
Room 9
Gressingham Building
Bowerham Road
Lancaster
LA1 3JD

Date:

Dear

I am an occupational therapist and doctoral researcher at the University of Cumbria. I am interested in trying out a new approach which looks at how people participate in activities in their everyday life, and the effect that this has on them. I am particularly interested in understanding the effects of this on people with memory problems.

I have enclosed a booklet which provides more detail about the research. This includes my photograph so that you know who I am. Please take the time to read the booklet and write down any questions that you might have. We can discuss this in detail when we next speak. Please feel free to include anyone who can help you with this decision.

I will contact you shortly to find out if you would like to participate in the research. You do not have to join the study, however I would be very pleased to work with you if you do agree to participate.

Kind regards,

Caroline Hampson

Occupational Therapist & Doctoral Researcher

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