Bangor University

DOCTOR OF PHILOSOPHY

Discourse and Dementia

Using positioning theory to explore whether an Appreciative Inquiry approach supports people living with dementia to challenge discourse

Davies Abbott, Ian

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Declaration

‘Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw’r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o’r blaen ar gyfer unrhyw radd, ac nid yw’n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.’

Rwy’n cadarnhau fy mod yn cyflwyno’r gwaith gyda chytundeb fy Ngrichwyliwr (Goruchwylwyr)’

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

I confirm that I am submitting the work with the agreement of my Supervisor(s)’

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Dedication

This thesis is dedicated to all the people living with dementia I have met during my clinical career who taught me to see the person first.

Acknowledgements

I am sincerely grateful to my supervisors, Dr. Jaci Huws and Dr. Sion Williams. The support and guidance they have provided has been invaluable during the journey of this thesis and my own journey as a researcher and a person.

I would like to thank all the participants who made the completion of this thesis possible. Thank you to all the healthcare workers who agreed to participate in their own time, each showing their commitment to improving the lives of people living with dementia. Thank you to all the family members/carers who immediately acknowledged the importance of the research subject and quickly allocated time for their involvement. Thank you to the lay people who despite many logistical and personal setbacks when attempting to arrange time for the research to take place, showed great determination and resilience to ensure their involvement. Most significantly, thank you to the people living with dementia whose contributions provided greater insights and outcomes than I had initially expected when starting this thesis. Together we embarked on a novel research journey, not knowing what the end result would be and I will always be grateful for their enthusiasm and amazing contributions.

I would also like to thank Dr. Catrin Hedd Jones whose help with finding the family member/carer group was crucial to the completion of the empirical work. Thank you to Professor Gill Windle who supported my application to discuss the earliest outcomes of the thesis at the Alzheimer Europe conference.

As a fellow PhD student using Appreciative Inquiry, I would also like to thank Dr. Sean Page. Our discussions were theoretically valuable and also personally valuable as we moved through our thesis journeys.

Finally, I would like to thank my wife, Sam and our children, Alys and Dylan for their patience and support.

Abstract

Aims: Appreciative Inquiry is a change methodology, which is based on the hypothesis that there is a positive core in every system. People living with dementia experience discourse, which malignantly positions them within society, potentially leading to negative consequences for them. This study aims to adapt the Appreciative Inquiry approach by using the positive experiences of people living with dementia to inform a mechanism of change to positively influence the discourse of family members/carers of people living with dementia, healthcare workers and lay people.

Methods: Appreciative Inquiry is adapted as the research methodology to support democratic social research and action when considering positioning theory in the discourse about people living with dementia. A four stage model was reconfigured, with a cohort of four people living with young onset dementia working through the first three phases (Discovery, Dream and Design). The outcome of these phases was presented to three natural discussion groups representing the three societal groups, whose discourse was analysed to consider whether the final phase of the model had been addressed (Delivery). Discourse data was analysed using positioning theory and thematic analysis.

Results: An original positioning theory framework was developed for the analysis of discrete discourse, with supporting models to describe the discursive route to what was perceived by people living with dementia as ‘ideal’ positioning. These original models/frameworks were supported by four conceptual findings. First, that people living with dementia are empowered to identify the requirements for positive verbal positioning using three phases of Appreciative Inquiry. Second, four positioning themes were identified to develop a framework to assess how people living with dementia experience verbal positioning by others. Third, that verbal positions are directly influenced by the outcomes of Appreciative Inquiry, resulting in a successful delivery. Fourth, there are five thematic positioning identities, which describe how the person’s experiences and view of themselves influence the positions they allocate. These identities act as facilitators and barriers to positive verbal positioning as defined by people living with dementia in an Appreciative Inquiry.

Conclusions: Appreciative Inquiry can be reconfigured to involve different participants across phases, retaining its generative and transformative potential, without foregoing its underpinning principles. People living with dementia can successfully complete an Appreciative Inquiry exercise with outcomes that have the power to transform the discourse about people living with dementia by other members of society. Positioning theory can be adapted to analyse discrete discursive themes to understand how people living with dementia are positioned by others and what influences this positioning. Social action can be influenced by people living with dementia using this adaptation of the Appreciative Inquiry methodology.

Personal reflection

I have a personal and professional relationship with dementia. The journey towards this thesis continues to be influenced by both of these elements. The inclusion of this personal reflection at the onset of the thesis is crucial to understand how my identity and relationship with dementia has forged my own biases in relation to discourse concerning people living with dementia. The account is influenced by the life story model of identity (McAdams, 2001) wherein self-understanding through narrative presents the means to give a person's life meaning and purpose. Identity is forged through a storytelling process that includes setting, scenes, plot and character (McAdams, 2004) that may be presented as chapters in the person's life story (McAdams, 1985). Individual chapters, which narrate my developing relationship with dementia, occur before my nurse training, during pre-registration nurse training and as a qualified nurse, leading to the present day as a nurse lecturer.

I had never considered a career in nursing until two weeks prior to the pre-registration course commencing. Until the age of twenty-five I have no recollections of meeting a person living with dementia or giving any thought to the subject of dementia. Leaving school at eighteen, I attended university in London to complete a BA (Hons) in English, Drama and Theatre studies. From there I moved between various jobs and went travelling. Constructing a narrative concerning how I would have positioned a person living with dementia at this time would be misleading. My only relationship with dementia was through the media.

The scene that led to my nursing career occurred in the summer of 2001. I was working in an office where the contracted work was almost completed. A colleague mentioned that he would be collecting an application form for a porter's role in the local general hospital and I decided to apply as well. It transpired we had missed the application deadline but I was left with a feeling that I would like to work in a hospital. I did not know what I would do there and did not see it as a long-term career but the desire was there. That evening I visited my parents and picked up the local newspaper were in the classified section was an advert stating that places on the BA Mental Health Nursing programme were still available at the local university. I contacted the university and had an interview two days later. Despite my lack of care experience or mental health knowledge, I was awarded a place on the course due to my academic background. Less than two weeks later I had started my journey.

During my first placement in a long stay mental health ward I can clearly define what could be considered a turning point (McAdams & Bowman, 2004) in my personal growth and positioning of people living with dementia. One lady on the ward had a dementia diagnosis. I would often sit, talk and hold her hand. I was aware that the care staff rarely engaged with this lady unless they were assisting her with personal hygiene, when she would become agitated and had caused physical harm to staff. Whilst sitting with this lady I was told on several occasions by staff members to be careful as she could be violent whilst others would see my conversations and simply voice a condescending, 'Awwh'. I discovered that the lady had been a teacher, had cared for children with learning disabilities and lived at home with her husband only two years prior to our meeting. At the time I was not familiar with the concept of positioning theory but was frustrated how this educated and caring lady was now being dismissed as uncooperative and violent by the care staff. No malice was evident in the staff's treatment of the lady but they had positioned her as a confused, violent dementia patient rather than a person. In my naivety I could have aligned myself with the staff but it was this scene in my life story when I made the decision, early in my nurse training, that I would work in dementia care and see the person, rather than a diagnostic or behavioural label. It was the first time that I understood how the culture of care can be detrimental to the psychological needs of the person living with dementia. Identities are provided by the culture rather than the individual (McAdams, 2001) and as the lady had been negatively positioned, I had also been positioned as the naïve but caring student who did not know any better. At that time this identity did not bother me, I knew that I lacked experience but if I chose to, I could rebel against my position. If the lady chose to rebel, it would only have strengthened her allocated position as an uncooperative and potentially aggressive dementia patient.

A prominent chapter in this life story occurred after several years of registered nurse practice. I was informing a gentleman about his diagnosis of Alzheimer's disease in the presence of his wife. Prior to the diagnosis and during the previous assessment it was evident that the couple loved and respected each other equally. The key turning point of this scene was the delivery of the diagnosis. The gentleman's wife stopped addressing her husband and began to speak about him as if he was not there. She then explained that she would look for music that he had previously enjoyed because ‘*they like that, don’t they?’* The diagnosis alone had altered the relationship between man and wife with the gentleman’s identity, in a brief moment, becoming Alzheimer’s disease rather than his own. I recall explaining that the diagnosis should not dictate how the gentleman should be considered but cannot say that my words had the requisite power to change the wife’s initial perceptions of her diagnosed husband.

It was during this period that I became aware of Appreciative Inquiry and attended training to become a facilitator. This training was paid for by the health board I worked for and was intended to inform organisational change projects led by a small group of trained facilitators. Several projects at the health board have been informed by the methodology and led to the publication of innovations regarding the inpatient experience of people living with dementia (Page, Rowett & Davies-Abbott, 2017), supporting transgender people living with dementia (Davies-Abbott et al., 2018; Page et al., 2016) and sexual safety on mental health wards (Page et al., 2020). Although I enjoyed the methodology I was initially cautious when facilitating inquiries with new groups. The focus on appreciation was often doubted at the start of inquiries by participants and I would readily admit to being initially unsure if it was a suitable methodology to address emotionally challenging subjects. However, each inquiry resulted in great creativity, positivity and most importantly, observable change. The basis for the methodology is that every system has a positive core and the experience of facilitating diverse and emotionally challenging inquiries has led me to concur with this hypothesis.

During the retelling of a life story it is often in the remit of the narrator to place oneself as the authority, creating an idealised self (McAdams, 2001). Whilst working as a clinical nurse specialist, I was well aware that I was often positioned as a ‘specialist’ but that this position was informed by a job title and would be lost if I moved into another role. Nevertheless, being employed as a ‘specialist’ created an expectation that I had knowledge and authority but in terms of my identity, I recognised the limitations of my understanding of living with dementia. A scene occurred during this period when I visited my grandmother who had a diagnosis of vascular dementia. I had knocked on her door but on answering, she looked at me without recognition and asked me if I was there to collect the window cleaning money. Although upsetting, the incident provided some understanding of why a carer might position their relative differently following diagnosis, if this reduced the emotional distress of the carer.

Since the start of my PhD I have entered a new phase of my life story, working full-time as a lecturer in healthcare sciences. It has therefore become more personally important to me that this study should consider the educational implications of the research, as well as those in clinical practice.

I have come to believe that people living with dementia are subject to verbal positioning, which ignores their personal identities and are often, through these positions, powerless to object and alter these to their favour. I believe that if we do not listen to the voices of people living with dementia, this situation will never change. People living with dementia require social action to ensure that their humanity continues to be recognised, no matter what stage of dementia they may be experiencing or the changes in behaviour or relationships this may be influencing. Dementia has altered my adult life to the point of what once had no meaning to me, is now something that I address daily. These life story scenes give an autobiographical understanding of why I have chosen to complete this thesis.

Language conventions

The term ‘Person’ or ‘People living with dementia’ is used throughout this thesis. This language has been informed by Alzheimer’s Australia (2015), Care Council for Wales (2016) and DEEP (2014), as well as the voices of people living with dementia in this thesis.

Chapter 1

Introduction to the thesis

1.0 Introduction

This thesis uses positioning theory (Davies & Harré, 1990) to explore how Appreciative Inquiry (AI) (Cooperrider & Srivastva, 1987) can be used to support people living with dementia to challenge and transform the discourse of other members of society. As far as the author is aware, this is the first study to reconfigure AI for people living with dementia as a mechanism to inspire change in people not directly involved with the initial inquiry. The overarching aim of the thesis was to understand whether an AI approach could be adapted for people living with dementia to influence the verbal positions offered by other members of society regarding people living with dementia. The wider context for the thesis is to promote the inclusion of the voices of people living with dementia in society and in the political strategies and guidelines, which affect their lives. The predominant focus of the thesis is the applicability of an AI methodology as constructed from a critical humanist (Plummer, 2001; Plummer, 2011) concern that people living with dementia are not verbally positioned as they would like to be, and therefore may be located malignantly as worthless and vulnerable.

The thesis adapts the process of AI as a platform for people living with dementia to share their positive experiences of discourse, to envision preferable discourse and create a platform to influence other members of society. As the thesis develops, discourse is analysed using positioning theory to ascertain whether a tool developed during the AI process can influence the positions allocated by other members of society. Emerging from the thesis is a reconfiguration of a traditional AI model to create an understanding of the discourse experiences and positioning preferences of people living with dementia. A new framework, the Balancing Framework, also emerges to analyse discretely focussed positions allocated to people living with dementia. A synthesis of the findings incorporates the facilitators and barriers for other society members to allocate positive positions in discourse as defined by people living with dementia.

AI is a collaborative methodology that enables participants to draw upon the positive aspects of an organisation. In the context of this thesis, the organisation is society and the subject of change is the discourse used in society regarding people living with dementia. The AI process concerns identifying a ‘positive core’ within the organisation, AI being structured around the belief that all organisations have elements of positive value that can be built upon. The thesis considers whether the AI methodology can be facilitated with people living with dementia as a means to explore whether this group can identify a ‘positive core’ when considering the concept of positioning theory and therefore how they are verbally positioned by other members of society.

Positioning theory is a social constructionist approach (Davies & Harré, 1990) concerned with how language is used by people to locate themselves and others in conversation and society. In positioning theory, positions are negotiable and fluid with positive positioning by others aligned to an acknowledgement of one’s rights and abilities. AI advances the identified positive aspects into alignment with the organisation’s change agenda. As part of the thesis the positive aspects of positioning were used to inform a video, designed by people living with dementia, to share how they would like to be discursively located in society.

The video was shared with three societal groups: health care workers, family members of people living with dementia and lay people with no professional, caring or familial role with people living with dementia. As the thesis develops, the discourse of the members of these groups is analysed using positioning theory to ascertain whether the tool developed by people living with dementia using AI can influence the positions allocated during group discourse.

This chapter begins by introducing the aims of the study. The rationale for the study is then presented by acknowledging the necessity to challenge discriminatory discourse and how this approach aligns to the current political context. This rationale is then supported by consideration of the critical humanist approach, which informed the study and how it is aligned to psychosocial dementia theories. Consideration is then given to how AI has been previously used to address the subject of dementia and how the approach aligns to dementia theories and critical humanism. The chapter closes by acknowledging the contributions of the thesis before a brief description of each chapter in the thesis.

1.1 Aims of the study

As the thesis focusses on the applicability of AI when used with people living with dementia, the aims are equally focussed on aspects of the AI process, as well as its relation to positioning theory. The verbal positioning of people living with dementia is the subject of change. Verbal positioning is directly related to positioning theory and is used in this context to describe how people are located in discourse using spoken language. When people find themselves objectionably located in discourse this may be referred to as negative or malignant positioning (Sabat, 2003), whilst agreeable positions can be viewed as experientially positive for the affected person. The AI process includes the appreciation of positive experiences and the appreciation of positive ideals. During AI, participants are asked to imagine what could be, unconstrained by the restrictions of present day limitations to consider their vision of the 'ideal'.

The study also focusses on adapting AI to ascertain whether the outcomes of three AI phases completed by people living with dementia can influence the verbal positions allocated by people outside of the original inquiry in the fourth phase of the inquiry. The thesis then considers why people may be influenced differently by the AI outcome.

The overarching aims of the study are captured in the following research questions:

- Can AI support people living with dementia to define a lived experience of ideal verbal positioning by others?
- Can the outcomes of an AI cycle with people living with dementia influence the verbal positioning of other groups in society?
- What factors influence the verbal positioning of people living with dementia by members of society aware of the AI outcome?

The first question is addressed during the analysis of the initial AI outcome involving four people living with dementia, which is discussed in chapters 4 and 5. The second and third question is informed by the discourse shared in the natural discussion groups, which is discussed in chapters 6 and 7. A synthesis of the research questions and findings is presented in chapter 8. The discussion in chapter 9 considers how the three aims of the study have been addressed by the thesis and how the principles of AI contributed to each phase of the methodology.

The first findings presented in this thesis represent the narratives of people living with dementia as delivered through the initial phases of an AI. The final chapters explore the discourse shared by other members of society and how individual experiences and beliefs influence their positioning.

1.2 Background: Dementia

Dementia is a clinical syndrome caused by chronic and progressive diseases of the brain characterised by the disturbance of multiple higher corticol functions resulting in cognitive dysfunction. Cognitive dysfunction is typically accompanied by changes in emotional control, social behaviours or motivation (World Health Organisation, 2004). Symptoms of the syndrome have been summarised as a collection of 'A''s, with *Amnesia, Agnosia, Aphasia, Apraxia* and *Abnormal Executive Function* typically included within the list of symptoms (Cummings, 2017; Reguindin, Meyer & Kuang, 2018; Jha & Mukhopadhaya, 2021). The most prevalent, *Amnesia*, describes the symptom of memory loss most commonly associated with dementia of Alzheimer's type. *Agnosia* is a sensory focussed symptom, which results in the person being unable to recognise sounds, objects or people (depending on the form of agnosia) despite otherwise having unimpaired sensory function (Kumar & Wroten, 2018). *Aphasia* results in a range of communication deficits including the comprehension or expression of language, as well as deficits to reading, writing and attention (Ellis & Urban, 2016). *Apraxia* indicates an impaired ability to complete an action despite the preservation of motor and coordination functions (DeRenzi & Faglioni, 1999). *Abnormal Executive Function* refers to deficits in goal directed problem solving, inhibitory control and working memory (Carlson, Zelazo & Faja, 2013). The presence of all of these symptoms is not required to meet the criteria for the dementia syndrome (World Health Organisation, 2004). Whilst attempts to characterise dementia within the boundaries of these 'A''s may be helpful for educational or synoptic purposes it belies the complexity of symptomology across the various forms of dementia.

There is no agreed number of sub-types of dementia although between 200 and 400 have been suggested (Dementia UK, 2021; Dementia Understand Together, 2021). There are estimated to be 50 million people living with dementia across the world (World Health Organisation, 2020) with approximately 885,000 people over the age of 65 living with dementia in the UK (Wittenburg, Hu, Barrarza-Araiza & Rehill, 2020). A further 42, 325 people, aged 65 and under are living with dementia in the UK (Prince et al, 2014), with estimates suggesting that 4.4% to 5% of all people living with dementia in the UK fall within this younger age bracket (Prince et al, 2014; Alzheimer's Research UK, 2020). In Wales, there is an estimated 46,800 older people living with dementia (Wittenburg, Hu, Barrarza-Araiza & Rehill, 2020). Based on the suggestions of prevalence in younger people with dementia across the UK, there are approximately 2238 people aged 65 and under living with dementia across Wales. There are expected to be over 1 million people living with dementia across the UK by 2024 (Wittenburg, Hu, Barrarza-Araiza & Rehill, 2020).

Alzheimer's disease is the most common form of dementia with suggestions that this sub-type occurs in 50-75% of all dementias (World Health Organisation, 2020, NICE, 2021). Although memory loss is the most common symptom, other cognitive deficits tend to develop as the disease progresses. Neuropsychiatric symptoms including anxiety, psychosis and depression may also develop during the early stages of the disease and although these may fluctuate in severity, they are likely to occur throughout the disease process (Lanctit etal, 2017). Alzheimer's disease has been primarily studied under two pathologies based on the disposition of Beta-amyloid plaque and neurofibrillary tangles of hyperphosphorylated tau in the brain (Weller & Budson, 2018). Cases of early onset Alzheimer's disease are typically caused by abnormalities in Beta-amyloid (Hampel et al, 2018) and rarer forms of the disease, typically observed in younger people, tend to be genetically determined (Bellenguez, Grenier-Boley & Lambert, 2020). A definitive diagnosis of Alzheimer's disease can only be made post-mortem, following the evaluation of brain tissue (Weller & Budson, 2018). Current pharmacological treatments include three cholinesterase inhibitors (Donepezil, Galantamine and Rivastigmine) and one N-Methyl-D-aspartate receptor (Memantine) although at present, medication offers only modest and symptomatic benefits, rather than prevention (Vaz & Silvestre, 2020). Non-pharmacological treatments for Alzheimer's disease, and dementia overall, are recognised as part of treatment although their cost efficacy is unclear and there is a lack of robust neurobiological evidence to support their effectiveness (Zucchella et al, 2018).

Vascular dementia is the second most common form of dementia, representing 20% of all cases (NICE, 2021). The term vascular dementia is an ‘umbrella term’ with several sub-types indicating the varying cerebrovascular pathologies. (O’Brien & Thomas, 2015). Vascular dementia often exists alongside other brain pathologies, most commonly Alzheimer’s disease. Unlike Alzheimer’s disease, the dominant symptom is not typically amnesia and it is common for people with vascular dementia to experience impaired executive function despite the preservation of other cognitive domains (Smith, 2017). Although medications, including hypertensives, may be used to manage cerebrovascular disease, there are currently no licensed treatments specifically for vascular dementia (O’Brien & Thomas, 2015).

Lewy body dementia presents in 10 to 15% of all dementia syndromes (Alzheimer’s Research UK, 2019; NICE, 2021) and is characterised by visual hallucinations, fluctuating cognition, Parkinsonism and sleep disorder (Kane et al, 2018). Lewy body dementia is frequently misdiagnosed, particularly when the person presents with typical dementia symptoms, without the presence of Parkinsonism (Mollenhauer et al, 2010), leading to frustration for the person and their family as well as increased healthcare costs (Olson, 2021). Dopaminergic treatment is recommended for motor symptoms and there is evidence of potential benefits on cognitive and behavioural changes when using cholinesterase inhibitors (Mollenhauer et al, 2010).

Frontotemporal dementia is another ‘umbrella term’ encompassing several neurodegenerative diseases. Whilst the prevalence of the disease is relatively small compared to more common types of dementia in older age, it is the second most common type of dementia observed in younger people (Pijenburg & Klaassen, 2021). Symptoms are typically observed in deficits to behaviour, language and executive function (Bang, Spina & Miller, 2015). Current therapies for frontotemporal dementia are limited although a small number of studies have suggested that selective serotonin reuptake inhibitors may improve behavioural symptoms (Herrmann et al, 2012; Hughes, Rittmann, Regenthal, Robbins & Rowe, 2015). There is little evidence for using cholinesterase inhibitors (Noufi, Khoury, Jeyakumar & Grossberg, 2019) and some evidence that Memantine may worsen symptoms (Glynn-Servedio, 2020). Whilst antipsychotic medication may be used to treat psychosis or agitation, this must be considered against its potentially harmful side effects (Young, Lavakumar, Tampi, Balachandran & Tampi, 2017).

Overall, women are more likely to be affected by dementia, accounting for 65% of all cases (Prince et al, 2014). Women are more likely to be affected by Alzheimer's disease with greater longevity, differences between genders during cognitive testing and the social implications of gender roles regarded as potential causes for this prevalence (Andrew & Tierney, 2018). Within genders, there are observable differences between ethnicities with Asian women having an 18% lower diagnostic incidence than white women, whilst black women are observed to have a 25% higher incidence compared to their white counterparts (Pham et al, 2018). Men have been observed to have an overall greater risk of Parkinson's disease dementia and chronic traumatic encephalopathy (Andrew & Tierney, 2018). Black men have a 28% higher incidence of diagnosis than white men, whilst Asian men have a 12% lower incidence than the latter cohort. However, prevalence rates also suggest that 53% of white men have received a diagnosis, compared to only 42% of black men (Pham et al, 2018).

For younger people living with dementia, diagnosis is more likely to be delayed due to the lower prevalence and the atypical presentation observed in this age group (Draper et al, 2016). Misdiagnosis is common and often associated with psychosocial issues such as the loss of employment or the breakdown of a marriage. (Pijenburg & Klaassen, 2021). The current focus on younger onset dementia is indicative of the lack of services currently available to meet the needs of people within this age group and their families (Roach, Bee & Keady, 2021) rather than an attempt to negatively position older people with dementia. However, the 'younger onset' term has been criticised as arbitrary as services should focus on the person and the impact on them, rather than their age (Dhandapani, Soundararaian & Bhattacharyya, 2021). The division of people by age may also suggest that whilst people under the age of 65 have 'unique' experiences, those in the older group are 'typical' (Tolhurst, 2016). These stereotypes are likely to result in poorer health outcomes and discrimination, as services are based on age rather than the person (Burnes et al, 2019).

These criticisms have some validity but also neglect the potential psychosocial effects of dementia on younger people and their families. In the younger age group, people are more likely to experience employment issues, may still be raising children or have significant debts (e.g. mortgage). Significantly, as the criticism demands that the person is put first, it is imperative that services listen to younger people with dementia who do view themselves differently to older people and believe that their distinct psychosocial needs are not currently being met by health services (Rabanal, Chatwin, Walker, O'Sullivan & Williamson, 2018).

1.3 Background: The need for social action

The thesis argues that the voices and experiences of people living with dementia must be included in the development of any strategies, which aim to address perceived stigmas or discrimination experienced by this group. Without listening to these experiences, strategies will lack an evidence base to consider how people living with dementia perceive their relationships with individuals and larger society. Perhaps more importantly, strategies will have no concept of what a world without this perceived stigma looks like from the perspective of the people experiencing its effects. The thesis is deeply entrenched in the belief that understanding these experiences is not enough to create a positive change and that social action is required, which directly informs public behaviour to overcome the ongoing experiences of stigma for people living with dementia. The thesis focusses on the application of discourse as a means to prevent and promote the stigmatisation of people living with dementia. People who are negatively positioned through discourse, may be subject to harmful repercussions, which result in the loss of rights and duties. Stigmatisation of any group or person is a social construct, which may be deeply embedded within an individual or larger culture. The thesis will acknowledge previous attempts to address stigma in relation to the language used about people living with dementia whilst arguing that changing the words a person uses does not directly alter the motivations of the person using those words. It is still possible to negatively position a person with 'dementia-friendly' language. The thesis has attempted to empower a group of people living with dementia to demand social action by other people, to alter their discourse to not only be 'dementia-friendly' at a surface level but also to respect people living with dementia's continuing citizenship.

Theories of citizenship are underpinned by a focus on rights, empowerment, agency and relationships (Bartlett & Nedlund, 2016). Citizenship is a socially constructed phenomenon and dementia activists have adopted the disability slogan 'nothing about us without us' to illustrate the social citizenship envisioned for people living with dementia (Thomas & Milligan, 2017). Social citizenship is arguably the most relevant citizenship theory to the experience of dementia (O'Connor & Nedlund, 2016) as it informs a macro to micro-level understanding of how rights, obligations and broad social apparatus inform an individual's sense of equality. At a micro-level, social citizenship supports an understanding of everyday citizenship (Bartlett, 2016), through an understanding of how an individual's attempts to self-define a place in their community are reciprocated by members of that community (Hopkins, Reicher & van Rijswijk, 2015). Social citizenship provides a status for people living with dementia where discrimination is absent and where they have opportunities to engage in society to their fullest ability (Bartlett & O'Connor, 2010).

People living with dementia can become active citizens, through social participation, by moving from the dominant deficit focus of discourse to one of living well (Birt, Poland, Csipke & Charlesworth, 2017). The inclusion of people living with dementia at a micro and macro level regarding their rights and social justices is necessary to challenge discrimination. This inclusion must include the narratives of people living with dementia (Keyes, Clarke & Gibb, 2017). Narrative citizenship theories have evolved from a belief that the current meta-level narratives about dementia are negative and encourage discrimination (Dupuis, Kontos, Mitchell, Jonas-Simpson & Gray, 2016). At a micro-level, narrative citizenship supports an understanding of how people living with dementia position themselves in relation to others and expands this to a macro understanding of how they are located within the social world (Baldwin, 2008; Clarke & Bailey, 2016).

Relational citizenship focuses on attentiveness, responsibility and responsiveness through the physical relationship between the body, sense of self and the world (Kontos, Miller & Kontos, 2017; Kontos & Grigorovich, 2018). This offers a bridge between the micro and macro level of understanding as issues concerning relationality and agency are crucial to human rights (Shakespeare, Zelig & Mittler, 2017), linking the theory to the fundamental underpinnings of social citizenship.

The overall meaning of citizenship is disputed and theories are currently emerging concerning the experience of people living with dementia. Theories of citizenship tend to overlap and being beholden to one theory would be unwise prior to listening to the narratives of people living with dementia, which is integral to all theories of citizenship. However, citizenship as a set of theories is useful when conceptualising social justice campaigns for society's marginalised groups experiencing stigma (Nedlund, Bartlett & Clarke, 2019).

Goffman (1963) proposed that the word stigma suggested that a person is perceived as different to others in a manner, which is unwanted and therefore the person is expected to feel ashamed. A person regarded in this way is: 'reduced..from a whole and usual person to a tainted, discounted one' (Goffman, 1963 p.3).

Stigma is applied through communication, typically resulting in a social stigmatisation which, informs attitudes of social disapproval for an individual or group due to their characteristics, which are deemed to be different (Rewerska-Juśko & Rejdak, 2020). The experience of stigma is reflected at different levels, with stigma experienced by individuals, families, and at a societal level (Werner, 2014). The concept of social health (Vernooij-Dassen & Jeon, 2016) applied to the experience of dementia suggests that healthcare practice, which tends to focus on the biological, psychological and social elements of care may neglect the person's remaining capacities to fulfil their potential and obligations. The application of stigma, which regards the person living with dementia as different and unwanted, denies ongoing capacities and the concepts aligned to social health, such as dignity, reciprocity and resilience.

The medical perspective perceives the losses experienced through dementia to be a construct of disease but the perspective of people living with dementia suggests that losses may be directly caused by the social responses of others. The medical discourse ignores the personhood and identity of the person living with dementia and is potentially dehumanising (Kitwood, 1997; Patterson, Clarke, Wolverson, & Moniz-Cook, 2018; Sabat, 2001; Sabat, Johnson, Swarbrick, & Keady, 2011). It is through discourse that the losses experienced, through social action, are activated. Discourse, informed by stigma, challenges the rights of people living with dementia to be regarded and treated as citizens and potentially, human beings. Positive relational practices can avoid these losses and uphold the person living with dementia's right to citizenship (O'Connor, Mann, & Wiersma, 2018).

Individually, stigma has the potential to lower self-esteem, self-worth and increase feelings of shame and embarrassment (Ballard, 2010; Harper et al., 2019; Mukadam

& Livingston, 2012). People living with dementia experiencing stigma have lower quality of life and well-being and are more likely to experience distress (Herrmann et al., 2018; Milne, 2010; Mukadam & Livingston, 2012). As stigma is socially driven, it also has social consequences, causing a reduction in social interactions, social inclusion and the loss of status (Devlin, MacAskill, & Stead, 2007; Garand, Lingler, Conner, & Dew, 2009; Kim, Werner, Richardson, & Anstey, 2019; Milne, 2010; Mukadam & Livingston, 2012). From a societal perspective, stigma distorts the services available to people living with dementia as it influences what politicians, and subsequently service providers, prioritise (Benbow & Jolley, 2012). This stigma impacts on the individual who may decide whether to use a service or not, and can be dependent on the social actions of politicians and providers (Benbow & Jolley, 2012; Burgener, Buckwalter, Perkhounkova, & Liu, 2015). The avoidance of services, due to stigma, may have significant health implications, including diagnostic delays (Mukadam & Livingston, 2012).

As most studies have tended to focus on the perspectives of carers and health professionals, there are few accounts of stigma from the perspective of people living with dementia (Urbańska, Szcześniak, & Rymaszewska, 2015). A systematic review regarding the experience of people living with dementia (Patterson et al., 2018) identified themes relating to social exclusion and being treated as the ‘other’. This finding aligns to suggestions that the discourse surrounding people living with dementia is often violent and encourages the perception of people living with dementia as the ‘other’ (Mitchell, Dupuis, & Kontos, 2013). Efforts to reduce stigma have also been criticised for promoting a sense of ‘otherness’, with people living with dementia often being distinguished as exceptional to provoke feelings of sympathy in others (Fletcher, 2019). Whilst this ‘othering’ may have benevolent intentions, it continues to position people living with dementia as different and therefore, more likely to experience stigma. Similar criticism has been voiced by Kate Swaffer, a person living with dementia, active in dementia research, who argued that the widely used term ‘dementia-friendly’ encourages, rather than reduces, division between people living with dementia and the rest of society (Swaffer, 2014).

Further findings of Patterson et al’s (2018) review included people living with dementia experiencing discourse and actions, which led them to being treated as ‘lesser’ people. They reported feeling disempowered, unheard and having their diagnosis misunderstood or questioned. Social responses also led to experiences were people living with dementia felt their identity was threatened, with consequences including feelings of worthlessness and being disregarded as a human being. The review included some positive accounts, including the perception of support given to individual people living with dementia and the ability of some people living with dementia to ignore negative discourse and actions when it occurred.

The experience of stigma for people living with dementia is not isolated to one country but is a global phenomenon. A study comparing perspectives of stigma, suggested British people living with dementia feel more stigmatised than those in Poland and Italy, although British people living with dementia were also found to be more open about talking about stigma (Lion et al., 2019). There has undoubtedly been a growing interest in addressing the stigma experienced by people living with dementia in research, as well as in global, national and local policies and action plans. Some researchers attempting to address this stigma have been criticised as people living with dementia are not always heard in their recommendations and therefore perpetuate the stigma they are trying to reduce (Swaffer, 2014). The development of guidelines and policies regarding dementia, over the last ten years, however, has illustrated a greater engagement with people living with dementia in organisational and political discourse.

1.4 Background: Living well with dementia

The term ‘living well with dementia’ has dominated the theoretical and political movement to resist the stigma surrounding dementia and encourage a positive portrayal of life with dementia. The term was prominently featured in the title of England’s national dementia strategy (Department of Health, 2009), which indicated that living well would include a choice of services, being treated with dignity and respect and a consideration of broader family issues, such as the needs of dependent children. Living well with dementia demands services engage with a person centred counter narrative against the traditionally negative framing of dementia, allowing them to recognise the potential abilities of people living with dementia and ensuring their service continues to develop to meet the needs of their communities (Clarke, Wilkinson, Keady & Gibb, 2011). The recognition of the person's capabilities was enshrined further into English policy through the Prime Minister's challenge (Department of Health, 2015), which emphasised the autonomy and decision making abilities of people living with dementia.

The narrative of living well with dementia can also be observed in the qualitative accounts of people experiencing the disease. Watson (2016), a person living with Alzheimer's disease, felt encouraged by the positive attitudes of people in her community who wanted to adapt to support people living with dementia and suggested that dementia was becoming a topic to be embraced rather than feared. Her own experience led her to suggest that it was possible to live well with dementia but not everyday. Reviews of qualitative accounts from people living with dementia since the turn of the century indicate that living with dementia encompasses negative and positive experiences but feelings of love, optimism, satisfaction and appreciation are frequently expressed (Górska, Forsyth & Maciver, 2018). Biographical accounts of living with dementia have grown considerably, promoting the need for meaning and purpose in the person's life (Bute, 2018; Graham, 2016; Mitchell, 2018) and directly advocating for living well within their title (Berry & Bunt, 2020). Studies have explored the indicators of living well with dementia, with personal attributes of self-efficacy, optimism and self-esteem regarded as vital (Lamont et al, 2020) and others indicating social factors, often external to the person, as key to quality of life and therefore, living well with dementia (Clare et al, 2014).

The movement has been criticised as 'living well with dementia' also implies the possibility of 'living badly with dementia' resulting in the requirement to redress the balance, with an acceptance of the positives without denying the negatives (Bartlett, Windemuth-Wolfson, Oliver & Dening, 2017). Whilst 'living well with dementia' remains embedded in English policy, the Welsh response indicated an acknowledgement of this demand for balance, with the country's Dementia Action Plan advocating for 'living as well as possible, for as long as possible' (Welsh Government, 2018).

1.5 Background: The political context

The global experience of stigma and discrimination through discourse was directly highlighted by *Overcoming the Stigma of Dementia* (Batsch & Mittelman, 2012b), a report published by Alzheimer's Disease International advocating urgent action to address the loss of citizenship and rights through social stigmatisation. The report promotes a process of reducing negative connotations held by society about dementia, increasing social empathy for people living with dementia, reducing fear of people living with dementia, resulting in reduced experiences of stigma for people living with dementia. In the same year, the World Health Organisation, aligned with Alzheimer's Disease International and published a series of dementia-focussed actions, including the demand for a global 'dementia-friendly' society to reduce the negative social consequences of dementia (World Health Organization & Alzheimer's Disease International, 2012). Responses to these global initiatives have been observed at national levels with the Alzheimer's Association in the USA, in partnership with the Centers for Disease Control and Prevention, publishing their own agenda to raise public awareness of dementia and educate practitioners to engage in sensitive and effective engagement with people living with dementia (Alzheimer's Association, 2013).

In the UK, it has been ten years since the introduction of the Equality Act 2010 (2010), which provided formal recognition of protected characteristics that could be potential triggers for stigma, including age and disability. The previous year in England had witnessed the publication of the country's first national dementia strategy (Department of Health, 2009), although it was six years later that the *Prime Minister's Challenge on Dementia 2020* (Department of Health, 2015) included accounts of what a world without stigma could potentially look like for people living with dementia: 'I have a sense of belonging and of being a valued part of family, community and civic life' (Department of Health, 2009 p.6).

In Wales, tackling inequalities and stigma experienced by people with mental health problems, applicable to people living with dementia, was included as a high level priority in *Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales* (Welsh Government, 2012). The Social Services and Well-Being Act (National Assembly for Wales, 2014) created fundamental principles to promote the inclusion of the voice of people using services, focussing on providing control and encouraging co-production. However, whilst applicable to people living with dementia, neither the strategy nor the Act provided a focus on the experience of dementia in Wales.

The publication of the *Dementia Action Plan for Wales 2018-2022* (Welsh Government, 2018) committed the Welsh government to promote the dignity, autonomy and rights of people living with dementia. The action plan included statements co-developed with people living with dementia, including:

> ‘We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it’
> (Welsh Government, 2018 p.4).

Co-developed statements related to experiences of inequality and stigma, with calls for people living with dementia to be accepted and included in their communities. From a healthcare perspective, people living with dementia demanded to be recognised and respected as partners in their care. The construction of the Action Plan included engagement with people living with dementia and the published Plan promotes the inclusion of people living with dementia in educating the public about the condition to reduce stigma. Whilst, these developments are undoubtedly positive, they can appear to exist in isolation, with dementia related plans and strategies appearing disconnected to other national programmes. A state of the nation report on equality and human-rights (Equality and Human Rights Commission, 2018), produced in the same year as the national Dementia Action Plan, does not specifically cite the experience of people living with dementia.

People living with dementia have developed their own responses to the issue of social stigmatisation. Concerns about the denial of rights was directly highlighted in the co-developed document, *Our Dementia, Our Rights* (Hare, 2016). There have been several ‘dementia-friendly’ language guides co-produced by people living with dementia in recent years (Alzheimer’s Australia, 2015; Care Council for Wales, 2016; Deep, 2014). Whilst guidance about language has coincided with the development of national dementia plans concerning the reduction of stigma, changes in language alone will not be enough to tackle embedded cultural stigmas. Swaffer (2014) raised concerns that language considered ‘dementia-friendly’ may potentially conceal negative attitudes and behaviour through a superficially acceptable discourse.

The political climate suggests that addressing the stigma experienced by people living with dementia is a local, national and global challenge. Unfortunately, whilst advocating for an end to stigma is a positive ideal, the anti-stigma agenda is undermined due to having little evidence to support its application (Fletcher, 2019). Although research about the denial of rights and beliefs is available, which has informed the development of strategies, the evidence base regarding how to reduce the stigmatisation of people living with dementia is lacking (Herrmann et al., 2018; Kim et al., 2019). This thesis attempts to address the reduction of stigma by challenging the discourse about people living with dementia. Whilst experiences of stigma are shared by people living with dementia participating in the research, these experiences are used to inform the creation of a film to reduce incidents of negative verbal positioning, rather than being a final outcome of the study.

1.6 Positioning the thesis: Critical humanism and Tom Kitwood

Critical humanism is an ontological approach, which has informed the methodological and analytical processes used in this thesis. The traditional view of humanism suggests that whilst the experience of being human is diverse, it is possible to understand the experience of being human as a universal truth. Critical humanism embraces the diversity of human affairs but focusses on the daily experiences of people, which cannot be removed from the context of their time, space, culture or relationships (Plummer, 2001; Plummer, 2011). Arguably, people do not exist independently but share a discourse and conscious empathy with other human beings (Kozlarek, 2020) whilst remaining individuals. These experiences have value to the individual and to the researcher (Plummer 2001, 2011) who must uphold the participant’s dignity and well-being during the research process (Plummer, 2011). The contextual importance of narratives in critical humanism aligns with aspects of critical theory, with subjectivity and creativity acting as foundational criteria in the approach (Plummer, 2001). Humanism supports a commitment to gaining knowledge through the appreciation of diverse human experiences and aims to deny attempts to prevent the sharing of these experiences. Critical humanism has evolved from a desire to understand ‘man’ to an endeavour to detect and attack inhumane actions (Kozlarek, 2020). The approach looks to ensure that the notion of humanity, continues to embrace the human individual. An approach, which seeks to recognise humanity and reject inhumane practices, can therefore be aligned with psychosocial dementia theories.

The psychological model of needs proposed by Kitwood (1997) remains a seminal work in the field of dementia theory and care. As critical humanism looks to understand the human experience in context, Kitwood's (1997) model also demands an understanding of the person's narrative to deliver genuinely person-centred care. Kitwood's (1990) theory of malignant social psychology is aligned to critical humanism, as both are concerned with understanding human experience and seek to denounce actions, which threaten the humanity of others (Kozlarek, 2020).

Kitwood (1990, 1993) challenged the deterministic and pessimistic medical view of dementia, highlighting the interpersonal impact on the progression and presentation of the disease. The term 'positive person work' is used to describe interactions, which uphold the person's well-being using the psychological model of needs. Malignant social psychology describes interactions, which diminish the personhood of the person living with dementia. Malignant interactions may occur due to a lack of appreciation of the individual person living with dementia or due to the assumptions embedded in the cultural context. The theory clearly acknowledges the proposal that the experience of dementia is dialectical, as the process of neurological impairment is acknowledged, alongside the interpersonal experiences of the individual person living with dementia (Kitwood, 1990). If a person is treated malignantly, their experience of dementia will be worse as their personhood, and therefore their humanity, are degraded. Dementia is therefore a social construction, as the diagnosis is achieved through a medical discourse whilst the experience of the person is the outcome of societal discourse and behaviour (Adams, 1996; Kitwood & Bredin, 1992). Discourse, which is derived from a social construction of stigmatisation towards people living with dementia, results in malignant interactions, which potentially inform malignant behaviours towards people living with dementia. The social stigmatisation of people living with dementia, which attacks citizenship and rights, is aligned to malignant social psychology interactions towards the psychological need of inclusion.

In this thesis, the analysis of discourse is informed by positioning theory and is therefore influenced by the theory of malignant positioning (Sabat, 2003). This theory was developed through an appreciation of Kitwood's (1990) theory of malignant social psychology. Malignant positioning occurs when a person is verbally positioned in a manner which is objectionable to them. The theory proposes that whilst a ‘healthy’ person may attempt to reposition themselves in a manner appealing to them, people living with dementia may be disadvantaged in these situations as their attempts to reposition themselves are regarded as dysfunctional. The person living with dementia’s attempt to gain control of their position is then regarded as problematic behaviour, which despite being caused by the initial malignant positioning, clarifies this negative position even further. Undertaking inquiries informed by critical humanism demands that these experiences are not only acknowledged, but also rejected (Kozlarek, 2020). It is therefore insufficient to research the social injustice of malignant social psychology and malignant positioning informed by the stigmatisation of people living with dementia, without also embracing the evolution of critical humanism to inform social action to counter these experiences.

1.7 Positioning the thesis: An appreciative approach

Hearing the narratives of people living with dementia and demanding action based on these narratives calls for a suitably structured methodological approach. The inclusion of informed voices of people living with dementia in research to advise action, is aligned to legal rights under the Mental Capacity Act (Mental Capacity Act, 2005); this supports the assumption of continued capacity, regardless of diagnosis, unless this is proven to be lacking. However, the majority of discourse within qualitative dementia literature is primarily related to the experiences of either personal or professional caregivers, rather than people living with dementia. This absence has been attributed to ethical difficulties including capacity when involving people living with dementia in research (Sherratt, Soteriou, & Evans, 2007) and more recently, a consideration that researcher led projects are often meaningless to their daily lives (Morbey et al, 2019).

Sinason's (1992) study countered the dominance of caregiver led narratives by providing literal accounts of people described as having intellectual disabilities during sessions of psychotherapy. These included the account of one person living with dementia sharing his emotional reaction to experiencing cognitive deterioration. Whilst there are numerous examples of people living with dementia being involved in qualitative research, Proctor's (2001) study was an attempt to address the lack of people living with dementia’s voices in research by interviewing four people living with dementia about experiences with care services. An outcome of the study included a recognition of power imbalances between people living with dementia and health professionals. The presence of memory impairment has been highlighted as a potential barrier for people living with dementia sharing their experiences in research although including people living with dementia in focus groups, rather than individual interviews, has been suggested as a mechanism to increase recall (Harmer & Orrell, 2008).

The direct inclusion of people living with dementia in research is not unusual, although examples of how the narratives of people living with dementia have informed social action through the research process are less common. Action research studies have previously been employed for people living with dementia to give their insights into the suitability of hospital environments (Hung et al, 2017). Mann and Hung (2019) recommended future examinations into the potential of Action Research in dementia, focussing particularly on Appreciative Inquiry (AI) as a means to create opportunities to maximise the impact of research. The evolution of AI from the foundations of Action Research is discussed in chapter 2.

AI demands the act of appreciating the experience of others as crucial to inform action. Although actions within AI projects may be related to improving organisational capacity or efficiency, the appreciative approach has also been applied to address power imbalances in social relationships between groups (Liebling, Price & Elliott, 1999; Lambdin-Pattavina, Desiderio, Gilmore, & Manohar, 2020).

Examples of people living with dementia being directly involved with AI processes are rare in the literature. However, developments relating to dementia have been attributed to AI projects including care workers and family members exploring the care of people living with dementia in hospital wards (Scerri, Innes, & Scerri, 2015), care workers considering how to embed person centred care approaches in dementia care (Scerri, Innes, & Scerri, 2019) and care workers and family members developing a conversational framework for nurses and health professionals during inpatient admissions for people living with dementia (Page et al., 2017). AI has also been discussed as a potential framework for intervention in dementia care, to appreciate the positive relationships caregivers may have with people living with dementia during periods of distressed behaviour as a means to foster stronger relationships (McCarthy, 2017). AI was used to consider the positive experiences of transgender people in healthcare to develop guidelines for healthcare workers caring for transgender people living with dementia (Davies-Abbott et al., 2018; Page et al., 2016). The process did result in the creation of written guidance although whether this led to actual social change was not subsequently measured.

In this thesis, AI is reconfigured to influence the social actions of societal members not involved in the first phases of the inquiry. Whether AI can instigate social change in people outside of the initial inquiry has also been considered in a local and national context through a diversity and inclusion project at a large research university (Mallory, 2020). The inquiry suggested that people, if unaware they were contributing to a stigma against another group, may be open change or at least open to listening. A study focusing on the initial generative stages of AI explored the positive experiences of family members when people living with dementia used hospital emergency departments (Watkins, Murphy, Kennedy, Dewar, & Graham, 2019). Although this study did not complete the full AI process, changes in care delivery by emergency department practitioners did suggest that the generative discourse created through AI could influence the social actions of people outside of the initial inquiry.

The narratives of people are the heart of the AI process, allowing participants to shape the inquiry rather than the researcher (Mallory, 2020). The appreciation of personal experience inherent in AI, allows researchers to understand the human experience from the literal narratives of participants. The act of sharing narratives allows the human experience to be emancipated. For this thesis, this emancipation is crucial as participants require power and freedom to challenge the positions allocated by other members of society towards them. Kitwood's (1997) proposition that malignant social psychology, and therefore malignant positioning (Sabat, 2000), should be challenged is a demand for social justice for people living with dementia. Social justice can only be achieved through social action. By informing social action through the empowered narratives shared during AI, the thesis embraces the tenets of critical humanism by recognising the human experience whilst seeking justice for inhumane experiences.

1.8 Contributions of this thesis

This thesis promotes social action in a variety of societal members and groups regarding the verbal positioning of people living with dementia. The use of AI as the research methodology is justified as it is a democratic process, which aims to emancipate the experience of being human, empowering both participants and researcher to design social actions to achieve social justice. These justifications allow the thesis to make contributions to the knowledge base regarding AI and positioning theory. First, the thesis reconfigures AI to successfully emancipate people living with dementia to share their experiences and desires regarding verbal positioning by others, whilst demanding action by other members of society. This finding supports a theoretical development of an existing AI process. Second, it empowers members of three societal groups to engage and react to AI, through the sharing of the initial outcomes of the methodology completed by people living with dementia. This identifies a generative and transformative power of AI beyond the participants of the initial inquiry. Third, through AI, it identifies an ideal world for a group of people living with dementia using positioning theory and through this, a framework for positioning theory analysis in relation to the identified ideal. This Balancing Framework illustrates a new approach to positioning theory analysis when exploring finite positional subjects and values. The Balancing Framework is a key theoretical development as it represents, as far as this author is aware, the first theoretically developed framework to visualise positioning theory in discursive contexts with negative and positive positioning allocations. Fourth, through positioning analysis, it identifies the barriers and facilitators for members of society to have their verbal positioning of people living with dementia influenced by the outcome of the AI. This suggests that whilst the transformative power of the AI outcome is accessible to all speakers, this accessibility is influenced by internal and external forces, individually attributable to each member of society. Finally, the thesis provides a novel understanding of how people living with dementia experience discourse and the discourse they expect from society. This is captured in the theoretical contribution of a final model, which connects three frameworks to describe how positively allocated positions are experienced by the person living with dementia, incorporating the positioner, the allocation of a position and the person themselves.

1.9 Structure of the thesis

The thesis consists of nine chapters, which are structured to provide an account of the AI phases, the development of analytical frameworks, their applications and the final synthesis and discussion.

Chapter 2: This chapter presents the research methodology. Following a foundational exploration of AI, positioning theory and natural discussion groups, their application in the thesis is presented.

Chapter 3: This chapter presents a scoping review, which was completed to identify how people living with dementia are verbally positioned by research participants in academic literature.

Chapter 4: This chapter reports on the conceptual finding that people living with dementia are empowered to identify the requirements of positive verbal positioning using the Discovery, Dream and Design phases of AI.

Chapter 5: This chapter reports on the conceptual finding of four positioning themes, which emerged from the AI process. The development of the Balancing Framework for positioning theory analysis is illustrated.

Chapter 6: This chapter reports on the conceptual finding that the verbal positioning of people living with dementia, by other members of society, can be directly influenced by the film created during the AI process by people living with dementia.

Chapter 7: This chapter reports on the conceptual finding of five thematic positioning identities as facilitators and barriers for allocating positive verbal positions, as defined by people living with dementia during AI.

Chapter 8: This chapter is a synthesis of the conceptual research findings. The final model illustrates that whilst positions may objectively meet the requirements of positive positioning they must also be accepted positively by individual people living with dementia.

Chapter 9: This chapter discusses the contribution to knowledge of the thesis before addressing the individual research questions originally presented in this chapter.

Chapter 2

Research Methodologies and Methods

2.0 Introduction

This chapter sets out Appreciative Inquiry (AI) as the research methodology to generate data regarding what constitutes preferable positioning from the viewpoint of people living with dementia and to transform the positions allocated to people living with dementia by three social groups. Positioning theory is set out as the method to analyse discourse in relation to the aims and objectives of this study. Natural discussion groups are set out as a valid approach to capture discourse within pre-existing group relationships in research.

The approach used during this study is described, and explorations are made of the ethical considerations, recruitment, the innovative application of the AI methodology and natural discussion groups. The chapter will conclude with a description of data collection and the subsequent analysis using thematic analysis (Braun & Clarke, 2006) and positioning theory (Davies & Harré, 1990), which informs the findings in chapters 4 to 7.

2.1 Methodology: Appreciative Inquiry

AI is a process delivered through a structured approach, utilising four distinct phases, known as the 4D cycle, to achieve positive systemic change (Cooperrider & Whitney, 2001). The four phases include Discovery, when participants use their experiences to identify the positive elements of their system or organisation. The Dream phase asks participants to envision what their system or organisation would look like in an ideal world whilst the Design phase grounds these visions in the positive realities shared in Discovery, to consider what may be. The fourth phase, Delivery or Destiny, asks participants to consider and instigate the practical actions required for positive change to occur. The process is democratic with participants encouraged to conceptualise unique and potentially innovative ideas to inform how change will occur. Language is integral to AI as it endeavours to generate discourse, which challenges preconceptions of what a system could be and through its democratisation, influence the eventual behaviour of participants. With its origins in the field of Action Research (Lewin, 1946), AI has negligible connections to the positivist paradigm in research, denying the precedence of factual measurement over practical function. The methodology also challenges the traditional deficit based, problem solving approach of organisational change (Cooperrider & Srivastva, 1987) through its exploration of a system's positive aspects The approach is aligned to the deconstructive, pragmatic paradigm, or a post-positivist paradigm, with its focus primarily on the practical application of socially constructed research rather than judging its findings as merely theoretical. Social explorations in AI occur democratically, with participants wielding the same potential power to contribute in the process and influence change.

Lewin (1946) in his initial writings about Action Research, a significant influence on the development of AI, regarded democratic social exploration as a mechanism to ease social conflicts, rejecting the applied objectivity of the positivistic approach. He advocated democratic approaches, which looked to formulate hypotheses relating to 'if so' questions, central to social sciences research. The democratic process is supported in AI as the researcher is regarded as an active participant within the social research, as well as leading the investigation and subsequent evaluations. Lewin (1951) believed that social theories could only be advanced through full democratisation and collaboration between participants and researchers.

As a distinct approach to social research, the practical origins of the AI methodology are found in the work of David Cooperrider during 1980, when his evaluation of positive and negative qualitative research data saw him drawn towards the affirmative results. The approach strives to identify the good things about an existing system, with concerns raised that focussing on a system's problems results in real and perceived problems being emphasised and amplified (Hammond, 1996). This does not mean that AI chooses to ignore negative aspects of the system but rather views positivity as a seed for generative discourse, which informs generative action resulting in changes, which overcome negative aspects of the system by focussing on positive solutions (Bushe, 2007). A core assumption held by AI practitioners is that all systems have positive attributes. As AI is built on the presumption that realities can be socially constructed (Bushe, 2001; Cooperrider, Barrett, & Srivastva, 1995), participants are encouraged to explore and identify new models and ideas to challenge the existing social construction through a process that is intrinsically *generative* (Bushe, 2007). *Discourse* is central to the process of AI and its contribution to the construction of *relational realities*, were realities are not purported to independently exist but live as multiple experiential truths (Van Der Haar & Hosking, 2004; Watkins & Cooperrider, 2000). Methodologically, the identification of positive values within a system is integral to AI but is secondary to the generative empowerment of participants (Cooperrider & Srivastva, 1987). AI has been described as having a *catalytic* (Whitney & Trosten-Bloom, 2002) effect as the process precipitates practical change, hereby moving social thought into action. As a catalyst, AI is also regarded as potentially *transformational*, although this potential is dependent on participant's willingness to engage in the process and their belief in the new reality (Bushe & Kassam, 2005; Faure, 2006). If the intrinsic qualities of the process are adhered to by AI practitioners, this challenge can be overcome if the research is genuinely democratic and empowered by an open discourse, which respects the positive narratives and generative outcomes shared by participants.

Whilst AI is a relatively modern methodology it has been increasingly tested as an affirmative and generative process, which results in democratically agreed actions when the desire to change is present and has the potential to use discourse to generate new ideas and concepts, socially and relationally construct new realities and physically transform systems (Cooperrider & Avital, 2004; Gergen, Gergen, & Barrett, 2004).

Historical origins of AI in Action Research

During the genesis of AI, its founders described it as a 'reconfiguration' of the Action Research approach to socially democratic change (Cooperrider & Srivastva, 1987), to reawaken participant's imaginations and allow the appreciation of a system's 'uncertainties, ambiguities, mysteries, and inexplicable, miraculous nature' (Cooperrider & Srivastva, 1987 p.166). These were qualities they considered Action Research had lost through its problem oriented approach, having failed to substantially advance social knowledge, in its conventional form or achieve its transformational potential (Cooperrider & Srivastva, 1987).

Action Research is fundamentally rooted in participation with social change regarded as only possible when the people asked to change are part of the process. The aim of the process is to not only study and theoretically understand practices but to change them as well. Lewin's vision of Action Research was to see it move away from the positivist paradigm whilst still retaining theoretical validity. His approach to change introduced a cyclical approach, which he termed, a ‘spiral of steps’ (Lewin, 1946). The four point cycle of change was described as plan, observe, act and feedback. It was regarded as an ongoing and progressive cycle (Riel, 2010) as participants continued to collaboratively instigate change during and following the research intervention. The cyclical process was inherited in AI through the development of the 4D cycle (Cooperrider & Whitney, 2001), with the underlying belief that the process advocates a progressive approach to change.

However, Action Research has been noted for its pursuit of action whilst neglecting the theoretical details regarding how knowledge is gained from its findings (Cooperrider & Srivastva, 1987; Green & Thorogood, 2004). The reconfiguration of the approach through AI has two objectives, the development of organisations but equally, the generation of theory (Cooperrider & Srivastva, 1987, 1999).

The fundamental problem solving approach of Action Research suggests that the systems within the research are inherently problematic. This is a concerning starting point for democratically developed research and change as participants are approached to take a deficit based approach to themselves and their system. The requirement to learn through *Appreciation*, rather than deficits and the *Generation* of theory, are key to the AI process and its reconfiguration of Action Research.

Appreciation

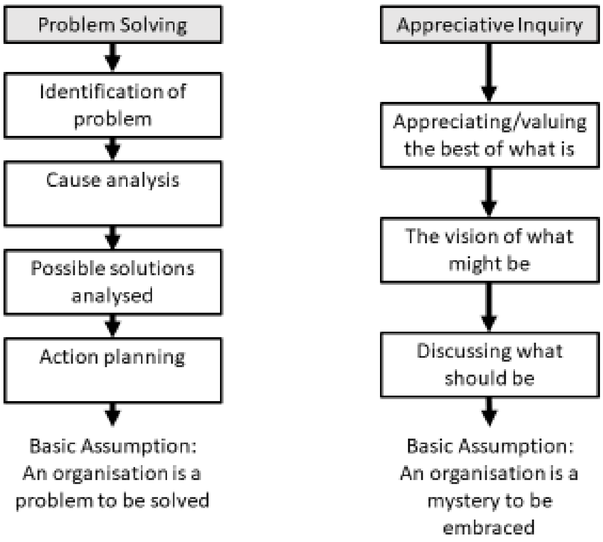
Vickers (1964) offered a concept of ‘appreciative systems’ based on theories of unconscious human perceptions during communication. These systems could be represented in organisations, societies, professions or other cultural designs. Whilst acknowledging the complexity of these systems, Vickers considered their appreciation to be a fundamental process in understanding what may need to change. Appreciation is presented as a complex process in a three part cycle, incorporating Reality Judgement, Value Judgement and Action Judgement (Vickers, 1968). Reality Judgement involves attentively singling out of an aspect of reality, Value Judgement is the perception of the aspect against what the perceiver considers ‘normal’ and Action Judgement is the action that is taken to move the aspect closer to the ‘normal’ vision. Appreciation is fundamentally driven by perception, with the cycle informed by an unconscious process (Vickers, 1964).

Whilst all appreciation moves through the same cyclical process, the perceptions of individuals affect their own ‘appreciative systems’, meaning that the same aspect singled out for attention during Reality Judgement will be perceived differently depending on the unconscious beliefs of the individual or system. The unconscious process means that some members of society may be more aligned to an affirmative viewpoint, whilst others are more inclined to use deficit based judgements. The conceptualisation of appreciation, outside of the cyclical model, illustrates the fundamental difference between the Action Research and AI methodologies. Whilst Action Research is limited by its deficit based beginnings, the act of appreciation allows AI to believe that all systems have a fundamental ‘positive core’ (Cooperrider & Whitney, 2001), which illustrates what gives life to the best things within the organisation. Within AI, human systems have been proposed to grow in the direction of their most persistent inquiries (Cooperrider, Whitney & Stavros, 2008), allowing inquiries, which are persistently appreciative of the system’s strengths, to grow in this direction.

The reconfiguration of Action Research proposed by Cooperrider and Srivastva (1987) in the development of AI is immersed in the appreciative concepts advocated by Vickers. However, Vickers’ proposal that appreciation could be used to identify what should be changed was also challenged by AI, as the former proposal remained aligned to the problem solving paradigm. Cooperrider and Srivastva (1987) proposed AI as a mechanism to move away from the deficit focussed approaches of Action Research, which had progressively lost sight of Lewin’s (1951) initial vision of adventurism and revitalisation. AI denies the belief of the problem solving paradigm that systems are problems that need to be solved, instead an inquiry begins with the basic assumption that: ‘An organisation is a mystery to be embraced’ (Cooperrider and Whitney, 2005 p.13).

AI illustrates the innovative movement between the problem solving approach and its own appreciative approach in Figure 1.

Figure 1: Problem solving and Appreciative Inquiry paradigms



Cooperrider and Srivastva (1987) also challenged Vickers' assertion that appreciation was a solely unconscious process and advocated AI as a methodological process that could be used by researchers to consciously and collaboratively appreciate the affirmative. This conscious appreciation is the backbone of AI as it is through this process that the 'positive core' of a system can be discovered. The 'positive core' is identified through the appreciation of affirmative narratives about a system and represents the system's strengths and virtues. The 'positive core' is the 'heart' of AI and represents both the beginning and the end of the inquiry (Cooperrider, Whitney & Stavros, 2008). It is here that the future of the system is revitalised, aligned to Lewin's (1951) vision, through the construction of the system from the conscious appreciation of its positive strengths.

Generation of ideas and theory

Gergen (1978) argued that the positivist paradigm was incompatible with the generation of social theory as positivist ideals, such as prediction and control, were invalid when attempting to understand social psychologies. Alternatives for social action, beyond the assumptions of the existing culture, require 'generative capacity' to challenge and reconsider what is taken for granted and therefore, are inaccessible through positivist social science. Social research should not be conducted by looking and recording at phenomena, as prescribed by positivist approaches, as its relation to social constructionism demands an interpretative and constructive approach to data analysis (Gergen, 1982). The move towards a less quantitative to a more generative and constructive methodology aligns with Lewin's (1946) original rejection of the positivist research paradigm. The value of interpreting reality, rather than attempting to rigidly quantify its existence, acted as a catalyst for the development of Action Research and the subsequent development of AI were theory is regarded as having value due to its generativity rather than predictive capacity (Cooperrider & Srivastva, 1987).

McNamee and Gergen (1999) argued that approaches, which aspire to generate new ideas, when examining larger systems, must be inclusive, with phenomena unlikely to be explained through the perspectives of individuals. They suggested that through 'relational responsibility', the inclusion of groups of people within larger relationships allows for greater generative capacity and also, in line with AI, reduces the potential of a deficit based approach as individuals are less likely to be regarded as blame worthy and members of the system recognise that they belong to the same social structure (McNamee & Gergen, 1999). It is only through co-construction and interpretation that new social theories can develop (Gergen, 1982).

A researcher aligned to the positivist paradigm will begin the research process with underlying assumptions of what they believe are the relevant 'facts' to be discovered, resulting in their subsequent observations and conclusions mirroring those 'facts' (Gergen, 1978). The positivist stance denies the fundamental value of generating new ideas and research as invigorating, with the paradigm described as: 'not the work of scientific analysis but that of engineering' (Moscovici, 1972 p.32) Moscovici's (1972) analysis bears a clear resemblance to later concerns raised about current practices in Action Research: 'Instead of explorers we have become mechanics' (Cooperrider & Srivastva, 1987 p162).

Gergen's theories added momentum to Cooperrider and Srivastva's (1987) refinement of the AI process during the early stages of its development (Reed, 2007). AI has been illustrated to have greater generative capacity than problem solving methodologies in research (Bushe & Paranjpey, 2015; Paranjpey, 2013). The generative capacity of the methodology is also well illustrated in the findings of this thesis, with the four phases of AI inspiring participant's to voice new ideas, which are subsequently interpreted to develop new theories. As AI aspires to inform social action, its generativity is crucial if the process is also to be transformational (Bushe, 2010). The aims of this thesis are immersed in the transformational potential of AI, which is also illustrated in the findings following the analysis and synthesis of the four AI phases. In its earliest form, a core concept of AI was that the development of new ideas could be a force for change (Cooperrider & Srivastva, 1987). The generative potential of the methodology is therefore crucial for its success.

Principles of AI

Five principles have been developed, which are regarded as crucial to AI practice. The principles evolved through the early conceptualisation of AI by Cooperrider and Srivastva (1987) and were subsequently clarified as further underpinning guidance was developed (Cooperrider et al., 1995; Cooperrider & Whitney, 2001).

The five principles are:

- The Constructionist Principle
- The Principle of Simultaneity
- The Poetic Principle
- The Anticipatory Principle
- The Positive Principle

The five principles will now be discussed prior to an analysis of the AI process.

The Constructionist Principle

AI embraces a social constructionist paradigm, dismissing the positivist stance, as organisations are regarded as living and human systems. The process motivates participants to unleash their creative imaginations, allowing their constructions of the future to be uprooted from their prior assumptions and open to inclusion without the presentation of hard factual evidence. Shared stories are the seeds, which allow the vision of the future to grow. Parallels can be observed between Gergen's (1982) social constructionist theory and the principle, whilst the process also mirrors McNamee and Gergen's (1999) concept of 'relational responsibility' as the future is constructed by members of the system, rather than individuals.

The first questions asked during an inquiry precipitate organisational change. In the AI process, the Discovery question (as the first phase) generates the first constructions of the system of inquiry. The material produced from these questions informs the initial vision of how the future of the system will be viewed and constructed. AI facilitators must be able to read, understand and analyse the human properties of the system by remaining open to the constructions shared during the inquiry.

The Principle of Simultaneity

In AI, both inquiry and change are regarded as simultaneous. As participants are asked questions to motivate them to think differently, there is an immediate intervention as the information gathered during the discourse illustrates inquiry, whilst the perceptual change demonstrates intervention. The acceptance of organisations as living, human systems means that the processes of inquiry and intervention cannot occur separately (Fitzgerald, Murrell, & Newman, 2001). When the system is considered and discussed, learning is inspired in participants to envision and construct the future. The principle is related to the initial Discovery question, which informs the initial sharing of experiences but also instigates the first changes in how the participants perceive and construct the system from that point. It is in this principle that AI’s movement away from Action Research is clearly illustrated. In Action Research the changes to the system are the end result of the inquiry, whilst in AI both actions are simultaneous and have equal value (Bushe & Kassam, 2005).

The Poetic Principle

AI views the constant co-authoring of human systems as open to creative interpretation. In this way, systems can be considered to have the same interpretive, inspirational and educative depth as great works of literature (Cooperrider, Whitney & Stavros, 2008). Interpretation does not belong in one point of time, allowing discourse concerning the past, present and future to inform learning and empower the conceptualisation of the desired system. The authoring act is poetic as the system is open to unlimited interpretation and AI allows for unlimited subjects to be studied, with the context of study influencing the subsequent creative process (Cooperrider & Whitney, 2001).

AI facilitators must support participants to realise the creative potential of this principle by supporting them to channel their attention and energies into the poetic authoring process. This support is crucial in ensuring the process is accessible to the participatory group (Reed, 2007). As with both the constructionist and simultaneity principles, social construction theory is fundamental to the poetic principle through its promotion of human interpretation.

The Anticipatory Principle

The basic premise of the principle is that images of the future will guide the current behaviour of organisational members. A future, which is imagined to be full of possibilities will inspire movements towards that future, whilst a future envisioned without possibilities, will inspire no action (Reed, 2007). Through the Discovery question, AI begins with a positive premise to guide a positively imagined future and the actions to make it happen. Positive images conceptualised by AI participants, which reconfigure the anticipatory vision: 'may be the most important aspect of any change process' (Cooperrider & Whitney, 2005 p.52).

The principle can be directly observed in the AI paradigm, with the anticipatory mechanism central to envisioning 'what might be' and 'discussing what should be'. Organisations can only continue to exist if their members anticipate their future and therefore take actions to ensure this future occurs. The principle is naturalistic to human behaviour as discourse is typically anticipatory (Cooperrider, Whitney & Stavros, 2008). Dialogue, which proposes expectations of the future is proposed to occur in natural human communication and subsequently guide action.

The Positive Principle

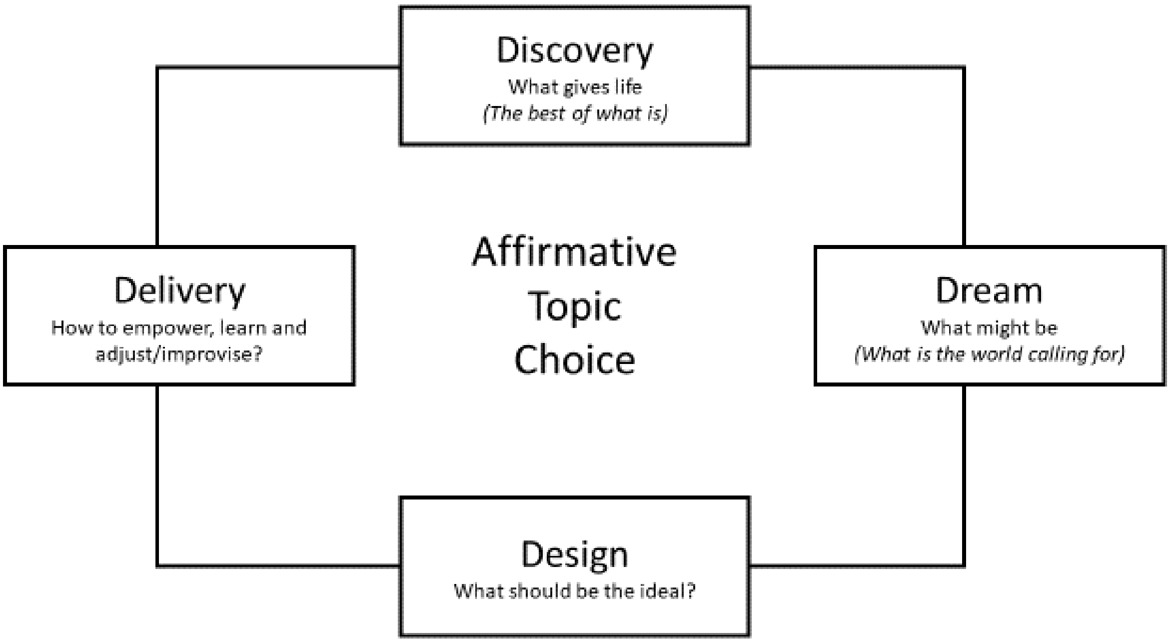
The act of positive appreciation, influenced by Vickers (1964, 1968), is central to the AI process. The methodology was developed through a denial of the problem solving paradigm of change. AI facilitators must ask questions, which are 'unconditionally positive' (Cooperrider & Whitney, 2001) to drive the positive discourse, which is crucial for change to occur. The positive images from this discourse have power and are key to AI, as these images instigate positive action.

Positivity provides energy to participants and sustains their interest to inform long term changes. For the participants to be involved in change, positive images must be present. Positivity is not only created through the context of the discourse but also the process of the inquiry. AI creates a collective of positive visionaries, who bond through the process, empowering them to experience hope, inspiration and triumph (Ludema, Wilmot, & Srivastva, 1997). A positively imagined vision of the future moves that vision closer to the present.

The AI process: The 4D approach

The 4D approach for AI (see Figure 2) was initially conceived by Cooperrider and Srivastva (1987) and subsequently methodologically clarified by Cooperrider and Whitney (2001). The illustration of the change process through a model can be traced to Lewin's (1946) 'spiral of steps', although the simplicities of both processes may find themselves open to criticism that through brief illustration the process of change is diminished into soundbites. However, the 4D approach would be better appreciated for its empowerment of the change process as it provides a practical and transparent grounding for creative and transformational discourse as a means to generate new ideas and deliver positive change.

Figure 2: The 4D approach to Appreciative Inquiry



The 4D approach was not designed as a strict formula but there is an expectation that systems will go through the four phases of the cycle when creating and delivering change (Cooperrider & Whitney, 2005), although the process may not always be followed in a linear way (Reed, 2007). A typical AI facilitation would, however, take an initially linear approach to the cycle, albeit with the expectation that participants would be able to revisit and draw upon the phases as required. In more recent conceptualisations and applications of AI, a 5D approach has been advocated (Priest et al, 2013; Quinney & Richardson, 2014; Stavros & Torres, 2018). The fifth element is typically entitled:

Define

It is in this phase when the focus of inquiry is agreed by participants, although there would typically be an initial contextual frame to guide the focus. In this thesis the traditional 4D approach was used as the definition of a topic was required to inform both the research design and to support the innovative approach to the methodology.

The four phases of the 4D approach will now be discussed.

Discovery

The immediate actions taken during Discovery announce the differences between this methodology and problem solving approaches and Action Research through appreciative questioning. Questions introduced during this phase typically ask participants to share their positive narratives regarding the system of inquiry. Once the first appreciative question has been asked, the inquiry has begun (Cooperrider, Whitney & Stavros, 2008), as participants are asked to reconfigure their experiences through appreciation, immediately changing their perception of the system. The purpose of the phase is to unearth, highlight and formulate the contributory factors, which provide nourishment and life to the system (Ludema, Cooperrider, & Barrett, 2001).

The affirmative questions demand the act of positive appreciation but also trigger the generativity of the process, as participants reframe their positive experiences as observations of the system’s worth. Questions that are surprising, build relationships between those located in the system, encourage participants to view their reality differently and are personally meaningful have been observed to have greater generative power (Bushe, 2007). To ensure the democratic process and to enrich the action of shared creativity, participants should ask the affirmative questions of each other (Bushe, 2012) whilst participation can be further enhanced by having participants ask the appreciative questions of each other and then having this group analyse the contributory factors, alongside the researcher (Cram, 2010).

Dream

The phase develops the ‘positive core’, Discovered in the earlier phase and encourages participants to amplify their positive narratives. These enthused narratives are accessed to envision the future of the system as having greater vitality and value than is previously foreseen by its current members (Cooperrider, Whitney & Stavros, 2008). Dream asks participants to develop a conceptualisation of the ideal world concerning the system of inquiry. To achieve this vision, the thinking and creativity must be quintessentially passionate (Finegold, Holland, & Lingham, 2002). The participants are encouraged not to limit their dreams of the ideal future but despite the indispensability of creativity and imagination in this phase, dreams are typically grounded in the experiences of the system’s history. The phase often involves a reconfiguration of the system’s history to envision a potential future, based on positive experiences, when the system will be ‘great’ (Cooperrider, Whitney & Stavros, 2008).

The ideas shared during Dream are encouraged to be unrestricted. Typical restrictions of the system should not limit the extent of the vision. Whilst typical visions of change may be hampered by considerations such as finances and relationships within the system, participants should be encouraged to remove these from their considerations as they will limit the generative process and prevent a true vision of the ideal system. Creativity and imagination are also applied to the practical achievement of the phase, as the Dream may be presented in limitless ways, with previous AI Dreams presented in song, poetry and role-play (Cram, 2010).

Concerns have been raised that AI and the Dream phase risk ‘unrealistic and dysfunctional perceptions, attitudes and behaviour’ (Roger & Fraser, 2003 p.77). However, such criticism ignores the principle of simultaneity as the Dream process endeavours to generate new ideas, which alter perceptions, but also initiates participants to move towards the ideal. The criticism is only applicable if the AI process regards Dream as an end point, ignoring the practicality of Design in the next phase.

Design

This phase involves the democratic construction of the system's future. Participant's articulation of the future emerges from the examples of positive experiences in the past. In this way, the Design phase is grounded in the narratives shared during the Discovery phase. Having moved through the unrestricted creativity of Dream, through Design the participants are reoriented to the system of inquiry (Whitney & Schau, 1998). A future design for the system is co-created through 'possibility propositions' (Cooperrider & Whitney, 2005), as the contributory factors describing 'the best of what is', discovered from lived experience in the first phase , are revisited by participants empowered with visions of the ideal system.

The phase may also include the application of 'provocative propositions' (Cooperrider & Whitney, 2001), which are affirmative, grounded and possibly time specific actions for participants. The language used in these propositions, typically endeavours to suggest an observable change that will occur in the new reality (e.g. *There will always be…*). During this thesis, the language of provocative propositions was discussed with participants and informed areas of their design but no specific, time oriented provocative propositions were created due to the innovative restructuring of participation in the four phases.

Design has been described as the crafting of the 'social architecture' of an organisation or system (Cooperrider, Whitney & Stavros, 2008). Through Design, the generative capacity of the participants democratically creates a grounded plan for their system's future, built upon a positive appreciation of their concrete experiences and passionate imaginations.

Delivery

In this phase the process progresses from planning into the actual implementation of change. It is here when understanding is developed regarding how improvements in the system may actually happen and considerations of how people in the system may learn from the knowledge that has been generated and adjust to the new vision of the future. It has been described as the transitional phase of AI, when planning advances to deployment (Boyd & Bright, 2007).

The phase is also commonly referred to as Destiny, as the plans made in Design are now ready to achieve their destiny. The Destiny phase has become more commonly referred than Delivery as AI conceptualisations have progressed, with the former title considered more befitting the methodology. The title of Delivery has been criticised as being too closely aligned with action planning and therefore more aligned with Action Research (Finegold et al., 2002). However, even in the context of AI, action plans may ensure that the positivity and generativity captured during the AI process is not lost once members of the system step out of the facilitated AI cycle. In this thesis, the title of Delivery has been retained as the phase describes the physical delivery of the participant's Design to the next groups of research participants. In this respect, the title of Delivery is wholly appropriate.

The aim of Delivery is to produce an outcome (defined by participants), which allows members of the system of inquiry to understand how they can contribute to the realisation of the organisational dream (Cooperrider, Whitney & Stavros, 2008).

2.2 Methodology: Positioning Theory

Positioning theory is primarily an analytical process concerning the discursive construction of relationships (Davies & Harré, 1990). The theory aims to understand how narratives inform action, moving away from the traditional linguistic focal points of semantics, syntax and pragmatics and concentrating on the act of speech within its context (Davies & Harré, 1990).The core exploration of positioning theory is the understanding of the explicit and implicit cognitive processes that establish the manner in which people act towards each other. Positions are generally attributed as personal rights or duties with the allocation of these positions demonstrating a moral order through the positioner's beliefs or actions (Harré et al, 2009a). A position is not the same as a 'role', with the latter dictating a typically fixed experience whilst a position is ephemeral, constantly evolving through the social context and narrative storyline (Harré & van Langenhove, 1991). The object of positioning theory is to understand how a person is situated through discourse and how situational developments alter this position. Allocated positions are regulated by the specific situation and the sensitivity of their context (Harré & Moghaddam, 2003), contributing a conceptual understanding of positioning within diverse social circumstances whilst also capturing the details of transitory social discourse. A position encourages a degree of social analysis, which is unrecognised by the concept of role (Davies & Harré, 1990)

The development of the theory was influenced by social theories advocated by Wittgenstein (1958) who regarded language as essentially social, rather than private, and critical to the social construction of reality. The theory is tied to the belief that human thinking is both a public and social function rather than a process that happens in isolation (Harré, 2004). Thinking is regarded as a non-isolative process as humans will inevitably be influenced by the opinions, advice and actions of others which in turn leads to the construction of rights and duties amongst people. It is here that positioning theory is also attached to the social theories of Vygotsky (1978) who argued that cognitive development is informed by language. Both, Wittgenstein and Vygotsky's theories sit within the social constructionist paradigm, reflecting the conceptual location of positioning theory. The theory's relationship with social constructionism and the writings of Gergen (1978) also provided a conceptual link to the AI methodology. The conceptual relationship to AI is also observed in the application of positioning theory as a method to analyse organisational change (Zelle, 2009).

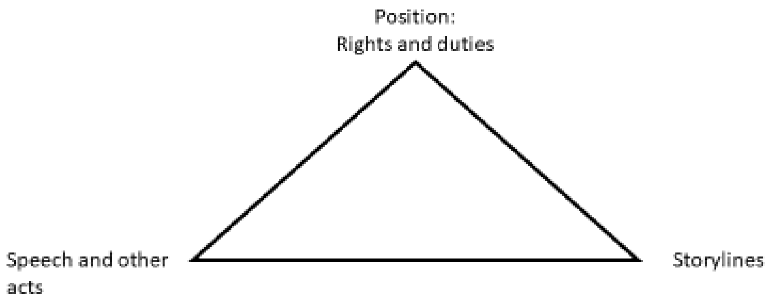
Positions may be created to characterise any facet of a person's experience or existence. Allocated positions shift as people are repositioned through a dynamic process were positions are accepted and rejected. The allocation of positions may be indirect or determined, although both approaches will influence the position's allocation of rights and duties. This is the movement between language, thought and action (Harré, 2008b). Although rights and duties may be assumed to denote a social power status they may equally be applied to any status e.g. being asked to remove the lid from a jam jar positions the person as 'the strongest' in a group suggests a biological rather than a social quality. Positions may be short lived and quickly altered as they are created and bound through relationships. All positions have a relational quality e.g. for one person to be positioned as 'the strongest', others in the same group must also be positioned as 'weaker' or 'the weakest' (Harré & van Langenhove, 1991). Although the choice of positions may appear limited, the positions allocated to an individual during discourse limit their choice of actions e.g. a new member of staff may be positioned as unable to provide a substantial contribution to a team meeting. The concept of power is crucial to positioning theory, as the allocated positions during discourse indicate which discursive members have the right to position themselves and others. The allocation of power within discourse, informs the understanding of the social reality: 'Positions are features of the local moral landscape' (Harré et al., 2009 p.9)

Positioning theory allows for the analysis of individual discursive actions and the larger social reality. As a research analysis tool it may identify and challenge stereotypes embedded in a social culture (van Langenhove & Harré, 1994). The evolution of positions occurs at an intrapersonal, interpersonal and intergroup level, revealing the complexity of social reality as meaning is constructed through interaction (O'Connor, 2007). The term 'position' has been described as wide enough to embody the diversity of human experience but also precise enough to give insight into the constantly changing social order (Harré & van Langenhove, 1999).

The Positioning Triad

The triad has surfaced to present the features of positioning theory and its analysis. The triad was originally developed by van Langenhove and Harré (1993) and subsequently developed by other theorists (Harré, Moghaddam, Cairnie, Rothbart, & Sabat, 2009; McVee, 2011). The triad is presented in Figure 3.

Figure 3: The positioning triad



Position: Rights and Duties

This area of the triad represents the position itself. A position is regarded as the attribution of rights and duties with rights, the allocation of entitlements and duties, the allocation of expectations (Harré, 2008a). Positions are not limited to the allocation of rights and duties but may also be observed in the justification of the allocations and may establish why the person can or cannot dispute the rights and duties attributed to them (Bamberg, 2008). The discursive justification for allocating rights and duties has also been described as ‘prepositioning’ (Harré, 2008a p.53). A similar variance between allocated positions is also observed in the distinction between performative and accountive positioning (Harré & van Langenhove, 1999). Whilst performative positions are observed in discourse, which results in action, accountive positions are positions, which cause no observable action and are typically ‘talk about talk’ (Harré and van Langenhove, 1999 p.21).

A duty should not be misaligned with a role, which is typically fixed, whilst a positioned duty may change within the next speech act. Within positioning theory, rights and duties are regarded as moral obligations, which emerge through the establishment of power. People with greater discursive power have the right to ascribe positions, whilst weaker members may not have the right to reject them (Harré, 2012). Positions themselves, however, are ambiguous and how they are interpreted by members of the discourse will vary (Davies & Harré, 1990).

How a person locates themselves and others, in a moral space, is the initial positioning act and referred to as the first order position. A second order position occurs if the first order is questioned, resulting in the possible renegotiation of a new first order. A third order position is typically an accountive position which takes place outside of the original storyline and involving different speaker e.g. a husband discussing an argument he had with his wife, with his mother. First order positions may also be created in this new storyline (Harré & van Langenhove, 1999; van Langenhove & Harré, 1994). The majority of first order positioning may be tacit, or unintentional, whilst both second and third order positions are always intentional (Harré & van Langenhove, 1999).

The power to dispute and renegotiate a position implies a moral right. The theory of malignant positioning (Sabat, 2003) can be traced to the earlier theory of malignant social psychology (Kitwood, 1997), occurring when positions are allocated, which implicitly reduce the rights and duties of the person. In both these theories, the focus of this malignancy has been people living with dementia although the same practices may be applied to any group, depending on the beliefs and values of the speakers. Malignant positioning results in the objectification of the person living with dementia and therefore results in the rejection of attempted second order positions, which are regarded as further evidence of their diagnosis (Sabat, 2007). Positioning, which arises because a person deviates from the expected 'norm', may suggest a personal, rather than moral positioning (Harré and van Langenhove, 1999).

Speech and other acts

These are the actual discursive acts, which encompass the storyline. Austin (1962) identified three distinct speech acts, which have continued to be applied by positioning theorists. The locutionary act is the utterance itself, which occurs simultaneously with the illocutionary act. The illocutionary act is the meaning of what has been said or what has been conveyed by the act of speech, not what happens because of the act itself. The perlocutionary act takes place outside of the locutionary act and describes what happens due to the illocutionary act or force. The perlocutionary act may be performed by somebody else, rather than the original interlocutor.

A parent who asks their child to wash the dishes has uttered the words (the locutionary act), at the same time they are conveying a message to the child that they want them to wash the dishes (the illocutionary act). In response the child may be persuaded to wash the dishes (the perlocutionary act) but could offer a second order position and ask for pocket money to complete the task. The illocutionary act in the latter outcome, conveys the meaning that the child is willing to wash the dishes but only for a reward. The parent may respond by paying the child, indicating a perlocutionary act as the child has persuaded the parent to agree with their demands whilst the washing of the dishes indicates a further perlocutionary act.

Speech acts do not occur in isolation, although they can be individually analysed, but are parts of a larger storyline. Analysis of speech acts within a storyline provide a greater understanding of the beliefs and bias within the interlocutory group. Analysis of the larger discourse provides greater social meaning as the positions allocated to the participants themselves are integral to this understanding (Davies & Harré, 1999).

Storylines

Interactions are bound by storylines, which may occur independently or simultaneously (Harré, 2008a). Storylines are influenced by the conversational history of those involved in the discursive process (Harré & van Langenhove, 1999).

Positioning theorists seek to understand why people choose their narrative stance during the storyline. People will choose a narrative to suit their own beliefs or desires regarding their rights and duties. Storylines are built upon the historical context of previous interactions, which could be a direct discursive relationship between the participants or a longer term historical context, which informs the beliefs of narrators (Harré & Moghaddam, 2003). A person who cites a past storyline to justify their current narrative may be less beholden to the truth than they are to offer a personally protective narrative (Bamberg & Georgakopoulou, 2008).

Storylines may be explicit if they are bound by rules e.g. in a wedding ceremony, there is an expectation of what the narratives will be and the language used to meet the requirements of the storyline. Implicit storylines are more improvisational and are therefore of greater interest to positioning theorists (Harré, 2008a). It is within the implicit storylines that the beliefs and bias of participants can be analysed.

The narrative selection during storylines can be aligned to the Discovery phase in AI. Whilst the Discovery question may be explicit, the discourse that follows is implicitly informed by the beliefs and bias of the processes participants.

Positioning levels

The methodological processes of positioning theory analysis, advocated in the works of Harré and methodologically similar theorists, have been subject to criticism due to a perceived lack of transparency and unclear data presentation (De Fina, 2013; Deppermann, 2013). Studies conducted and influenced by Harré’s approach to positioning theory have been regarded as potentially harmful to the methodology: ‘Their theoretical and empirical content is vague at best, if not plainly ambiguous and self defeating’ (Deppermann, 2013 p.4).

Criticism has also emerged regarding the limitations within Harré’s concept of positioning theory. Criticis have questioned the position of discourse as the sole mechanism in building the moral framework for how positions are allocated, instead suggesting that people have greater agency over their attribution of positions, which are formed beyond the confines of the current storyline. Positions should be evaluated as being driven by the identities of the interlocutors, rather than individual identities being driven by periods of discourse (Bamberg, 2003; Bamberg, De Fina, & Schiffrin, 2007).

Bamberg (1997) proposed three levels in which positioning takes place and advocated a positioning analysis using the three different levels as questions. The proposition has been celebrated as studies using this method of analysis have had a methodological rigour not observed in other studies involving positioning theory, which have typically displayed their analysis through illustrations of transcribed discourse (McVee, Silvestri, Barrett, & Haq, 2018). The three levels of positioning are:

Level One

> *'How are characters positioned in relation to one another within the reported events?'* (Bamberg, 1997 p.337)

This level explores how the characters within the discourse are constructed. This includes the attribution of rights and duties whilst allusions to discursive power may also be present at this level. Malignant positioning may also be observed depending on the characters involved in the discourse.

Level Two

> *'How does the speaker position him or herself to the audience?'* (Bamberg, 1997 p.337)

At this level, the analysis explores what the narrator is saying about themselves. Through their narration, the speaker may present themselves as possessing or lacking qualities, for example, a narrator may wish to position themselves as knowledgeable. At this level, the speaker may also offer advice or attribute blame.

Level Three

> *'How do narrators position themselves to themselves?'* (Bamberg, 1997 p.337)

It is at this level were speakers construct, propose and attempt to claim their identity. Analysis at level three, considers what overall meaning is being conveyed and what is being communicated beyond the current storyline. The analysis of the speaker's identity can be considered a 'decontextual' position (Bamberg, 1997 p.341). Whilst positioning theorits had previously suggested that any positions were indicative of a wider social and cultural meaning (Davies & Harré, 1990), the three part analysis indicates that a wider understanding is available as analysis reaches level three, although this level of analysis may not be possible during all discursive events (Bamberg, 1997; De Fina, 2013).

2.3 Methodology: Natural discussion groups

Lewin's (1946) application of Action Research attempted to raise the self-esteem of an ethnic minority population whilst integrating them further into the majority. The research used group discussions as a mechanism to understand the ideologies and stereotypes held within the groups, discounting these beliefs as individual traits but instead, situated within the group's culture. Lewin considered changes in beliefs to be dependent on the movement of the group as a whole. As the research was based on the development of pre-existing groups, the research groups were naturally designed as the individuals within them did not come together for the research alone.

Natural groups

Using naturally occurring groups in qualitative research challenges the positivist paradigm's approach to group discussion in research. Lincoln and Guba (1985) advocated a naturalistic paradigm in qualitative group research were, unlike the positivist approach, multiple realities could exist and be socially constructed, hypotheses could be accepted as contextual, rather than global and inquiry is regarded as valuable. Natural groups are not focus groups, brought together for the research alone (Putnam & Stohl, 1990) and tend to be used when researchers require a purposive sample (Patton, 1990). Natural group design tends to be used when the researcher wants to explore the interactions between participants (Kitzinger, 1995). Participants in a naturally occurring group will already be socially influenced through face to face communications with their peers, whether these are family members, co-workers or friends. Using these natural groups in research discussion encourages open dialogue as people are more likely to share their views with other people who they believe share their values (McGuire, 1985). A natural group therefore maximises interaction during discursive research and provides access to the culture of a pre-existing social group (Green & Thorogood, 2004). Natural groups are also an appropriate methodology when the research includes sensitive subject matter or is dependent on the social experience of its participants.

A natural study design was used in Myers and Bishop's (1970) investigation regarding racial prejudice in high school students. The study used natural group discussion as a mechanism to reduce racial bias in the population although it observed no significant changes in those with long term negative bias and could not distinguish what part of the discussion may have influenced any positive attitudinal shifts. This study shared the qualitative value of other studies using natural group design but could not identify the mechanism of change, due to the only mechanism being the group's discourse and the lack of an appropriate analysis tool. As established, in this thesis, AI and particularly the Delivery phase are being tested as a means to influence societal groups and positioning theory will be used to analyse the discourse of the natural groups included. Lewin (1946) foresaw the difficulties of recording the impact of group discourse and advocated rigorous evaluation.

The use of a natural discussion group rather than a natural focus group aligns with Lewin's and AI's democratic principles. Whilst facilitators in focus groups take a peripheral or observational role, a group discussion allows the facilitator to investigate alongside the participants (Parker & Tritter, 2006). Whilst the facilitator would not want to disrupt the naturally occurring discourse, the ability to interject and encourage participants is crucial to the democratic process already established in AI. If groups are well facilitated there should not be a significant requirement for the facilitator to interject, as participants during research group discussions are aware of the research context and are likely to remain focussed on the subject (Green & Thorogood, 2004).

Alignment with other methodologies

Alignments to both AI and positioning theory have been acknowledged in the previous discussion. In this thesis, three natural groups were brought together to discuss two fictional case studies either side of viewing an outcome from an AI workshop completed by people living with dementia. The subsequent analysis of each group can therefore be viewed as three distinct case studies. Observing the natural groups as natural case studies allows the application of positioning theory to reach level three of Bamberg's (1997) positioning analysis, as hierarchies of power beyond the context of the immediate discourse and the history of participant's practical experiences and emotional attachments are observed. Using Bamberg's (1997) positioning levels and the Balancing Framework, developed through the AI process, provides an objective analysis of three natural case studies created through the discourse of naturally occurring groups. Case studies, which are delivered naturally, offer much to the understanding of group processes (Yin, 2009).

The central aim for the thesis is whether an AI outcome created by people living with dementia can influence the positioning of people living with dementia by other societal groups. The use of natural groups is crucial to answering this question but also aids the methodology. Group development and learning is more likely to occur when the group members feel that their discourse will not be met with negative repercussions (Edmondson, 1999). Using natural groups can therefore encourage discourse, reassure participants and facilitate learning. Lewin's (1946) proposal for Action Research was that through research methods, social change could occur whilst further social research outcomes were generated. AI was a reconfiguration of Action Research to overcome its failings to meet Lewin's ideals. Using natural groups facilitates social change inspired by AI and inspires the generativity crucial to AI.

2.4 Research Design

2.4.1 Ethical considerations

Ethical Approval

An application for ethical approval to undertake the research was submitted to the Bangor University Healthcare and Medical Sciences Academic Ethics Committee on 18.03.2018. Full ethical approval was gained from this committee on 10.05.2018. Approval for the research is displayed in Appendix 1.

Consent

All participants in the research chose to engage voluntarily, without coercion and had the right to withdraw from the study at any point. Consent was recorded on a written form, which can be viewed in Appendix 2. Consent was informed through verbal contact with participants prior to the research day and the provision of a study information sheet describing the study procedures and the expectations of participants if they provided consent for the study. Study information sheets were tailored for each participatory group and can be viewed in Appendices 3 – 6.

To have full participation in the study, participants were required to agree consent for:

- Active involvement in the research process (AI or group discussion).
- Information collected being used in the study
- Having the information, from the study, stored for three years following its completion.
- The information collected to be used for analysis.
- Being filmed as part of the study.

Requesting consent for being filmed differed between the AI group and the three discussion groups. To complete the research there was an expectation that participants would consent to having their contributions to the research filmed. For the discussion group members, their interactions were filmed during the case study discussions. Consent was required for this filming and for the films to be viewed by the researcher to complete the subsequent analysis. The AI group were required to consent to filming, as part of the Design phase of the process. This film would then be viewed by the three discussion groups as part of the study. Filming in this group asked participants to consent to sharing information through a film that would be viewed by the discussion groups. There was no obligation for the participant to physically appear in the film and the options for the researcher to read out their part in the Design for the recording or have the contribution displayed in words on the screen were available. All four participants, however, did consent to appearing in the film.

Confidentiality

Discussion groups were filmed and the recordings were used for data analysis. These recordings could identify participants and were kept in a secure location and only used for data analysis. Transcriptions of the recordings, required for data analysis, were anonymised. Each participant was provided with a code, allocated to signify the social group they represented and their physical position within the group during filming e.g. the health care worker seated at the furthest left on the recording was coded HWA. A password protected electronic file on an encrypted computer at the university site was created to hold the logs of the codes and participants.

The AI group, as part of the consent procedure, were informed that they could withhold any information they chose to during filming. This included the option of using a pseudonym during the creation of the film during the Design phase. All four participants wanted to use their real names in the film when it was shown to the three discussion groups. The film was stored on password protected electronic file on an encrypted computer at the university site. For data analysis and the writing of the thesis, pseudonyms were created for the four participants to protect their anonymity.

Any publications or presentations that have arisen, or will arise, following this thesis will only refer to pseudonyms of AI group members and codes for discussion group members.

Capacity to consent

The involvement of people living with dementia in the study does raise the issue of capacity for consent. All participants provided informed, written consent on the day of the AI workshop. Participants were presumed to have capacity using the ethos of the Mental Capacity Act (2005). The researcher met with the participants two weeks prior to the AI workshop to explain the requirements of the study and provided a study information sheet to each participant. The details of the study were revisited on the date of the AI workshop and all four participants were able to understand the relevant information prior to giving their informed consent. As one participant chose to film their section of the AI Design phase on a separate day, the study details and consent were revisited again with this participant, on that day, who was able to recall and understand the details of the study prior to filming.

At the time of the study, the researcher was working at the local health board as a Clinical Nurse Specialist in Older Person’s Mental Health. In this role, the assessment of capacity was a regular part of the role and therefore, the assessment of capacity for this study was unproblematic.

Debriefing

Debriefing sessions were incorporated into the ethical approval process for all participants following their involvement with either the AI or a discussion group. The debriefing for the AI group occurred following the completion of the AI phases. The researcher provided time for questions regarding the research process but as the AI process was driven by the group, there were few questions about what had happened but participants did suggest that they had enjoyed using the methodology and understood how the film they had created would be used during the next phase of the research. Commentary about the AI process was also shared by participants during the workshop and is included in the thesis findings. The researcher also offered individual debriefing for any participants who wanted a private debriefing session but no participants accepted this offer.

The three discussion groups were offered a debriefing session following the completion of their part in the study, during the same day or on a subsequent day. These groups were also offered a dementia awareness session, to answer questions they may have about dementia after the study, separate to the research day and open to members of the same social group, who had not been involved in the study, if the participants consented to their involvement.

The healthcare worker group engaged in a short debriefing session following the discussion group. A dementia awareness session was delivered to this group, two days after the completion of the discussion group. The lay people group were debriefed following the discussion group. They declined the dementia awareness session. The family member/carer group were debriefed following the discussion group. They declined the dementia awareness session. All participants were asked to discuss any support they required following the study regarding dementia. At the time of the study, the researcher role provided substantial access to support services regarding dementia. No participants required this support.

Recruitment

Due to the design of the study, particularly the use of natural groups for all participant groups, a selection bias is immediately acknowledged. Inclusion criteria were developed for the four groups:

AI group: People living with dementia

- A person with a diagnosis of any sub-type of dementia.
- A member of the same social group as other people living with dementia in the study.
- Capacity to consent to the study and recording.
- Awareness of their dementia diagnosis and willing to share this within the study.
- Willing to engage in the AI process.

- Available to attend the workshop and filming day(s).

The AI group was identified through a person living with dementia who was aware that the researcher was looking for a group and through this contact the group consented to an initial visit to discuss the research. The group met regularly to socialise in a public house and four people living with dementia consented to being involved in the study.

Discussion group: Healthcare workers

- Professionally qualified or unqualified healthcare staff who regularly deliver face to face care to people living with dementia.
- A member of the same workforce as other healthcare workers in the study.
- Capacity to consent to the study.
- Willing to engage in the discussion group and view the AI film.
- Available to attend the discussion group day.

The researcher visited a care home and was given consent to provide staff with information sheets. However, when attempting to arrange a time to complete the discussion group, a date could not be identified with the service. A fellow researcher was aware of a care home, who had voiced an openness to being involved in research and the researcher contacted the manager by email. Following an initial meeting with the manager and a subsequent meeting to talk to the staff, a date was arranged for the discussion group and seven healthcare workers consented to the study.

Discussion group: Lay people

- No current caring responsibilities for a person living with dementia.
- A member of the same group as other lay people in the study.
- Capacity to consent to the study.
- Willing to engage in the discussion group and view the AI film.
- Available to attend the discussion group day.

The researcher was made aware of a group who met to play whist every week by a vicar who was aware that recruitment for the study was underway. I contacted the group who consented to my visit. The group members were provided with verbal information and the study information sheets. Identifying a date when group members and a site were available proved difficult. One date, which had been agreed, was cancelled due to the agreed location becoming unavailable. Another date was cancelled due to the death of a friend of the group whilst another was cancelled due to the researcher experiencing a bereavement. During these difficulties, in which I made regular visits to the group, I asked whether the group were still agreeable to their involvement with the study. Throughout this period, all group members remained committed to completing the study. On the day of the discussion group, six lay people consented to the study.

Discussion group: Family members/carers

- A close relative of a person living with dementia (a person directly related to the person e.g. wife, husband, son, daughter, in-law or someone with a close caring relationship).
- A member of the same group as other family members/carers in the study.
- Capacity to consent to the study.
- Willing to engage in the discussion group and view the AI film.
- Available to attend the discussion group day.

Family members who attended the same group as the people living with dementia in the AI group expressed an interest in engaging with the discussion group. However, due to illness within the group, this could not be arranged. Some of the family members related to people who had engaged in the AI group also offered to be involved but their number was insufficient. A group was identified through a colleague at Bangor University who was aware of a work premises where a group of people were close family members to people living with dementia. Following contact with the site, the group consented to information sharing and four family member/carers consented to the study on the day of the discussion group.

Sample

The minimum number of participants acceptable for the AI group was 4, with a maximum of 6. The number was chosen due to the innovative use of the methodology and the unknown requirements of the researcher to support the people living with dementia during the phases. For the discussion groups, a minimum of 4 participants were required, with a maximum of 8. Groups of this size were chosen to ensure that discourse was available for group analysis but with a limited group size due to the depth of analysis required for each participant.

Participant numbers by gender are presented in Table 1.

Table 1: Research sample

	Number of participants		
Group	Male	Female	Total
AI: people living with dementia	2	2	4
Discussion: Healthcare workers		7	7
Discussion: Lay people		6	6
Discussion: Family member/carers	1	3	4
	Total number of participants:		21

The study design dictated that the first three phases of AI were completed by people living with dementia. Four participants agreed to take part in the study during a meeting attended by people living with dementia and their relatives as part of their regular social contact. The group, led by the attendees, met at least once a month, usually in a public house, to socialise with each other. The participants had not known each other prior to their diagnosis of dementia and had joined the group at various stages since their diagnosis. The author was referred to the group by a person living with dementia who was aware of the recruitment requirements of the study although they were unable to participate in the study themselves. During the initial meeting, potential participants were provided with the information sheet, which was revisited prior to the study to ensure that all participants were fully aware of the contents of the study prior to agreeing their involvement. During the consent process, the participants agreed to use their own names during the film, shown to the natural discussion groups. They did not consent to their real names being presented in this thesis. Therefore, the names used in this thesis are pseudonyms. A summary of the participants is included in Table 2.

Table 2: People living with dementia participants demographic information

Pair Group	**Participant**	**Diagnosis**	**Gender**	**Age**
1	Pauline	Mixed type (Alzheimer’s and vascular dementia)	F	64
	Colin	Alzheimer’s type dementia	M	64

2	Gavin	Frontotemporal dementia	M	56
	Sue	Vascular dementia	F	60

The age of the participants locates them within the parameters of what is considered young or early onset dementia (under the age of 65). The inclusion of younger people living with dementia in this thesis was not indicated by the research design but rather through the process of identifying an existing group of people living with dementia who consented to the study. The experience of living with young onset dementia has been suggested to be experientially different to living with dementia in older age. There may be specific impacts due to the person's younger age particularly regarding their life trajectory and the effect on their relationship and roles (O'Malley et al, 2021). Younger people living with dementia have described their own sense of lost identity, particularly regarding losses in employment and changes in parental and spousal relationships, which they have described as a reflection on how they are perceived by others and how they perceive themselves (Greenwood & Smith, 2016; Harris & Keady, 2009).

The early onset of dementia has been recognised as particularly damaging for the person's children who witness their parent experiencing perpetual negative changes (Sikes & Hall, 2018). The needs of younger spouses have been described as similar to older spouses but with the former tending to require more social, general care and administrative support (Warwrziczny, Pasquier, Ducharme, Kergoat & Antoine, 2017). However, younger people living with dementia have rated their quality of life higher than it has been perceived by their caregiver (Baptista et al, 2016) although there have been few attempts to compare the quality of life of younger people living with dementia compared to their older counterparts (Bakker et al, 2014). The experience of health and social service support has been corroborated as generally poorer for younger people living with dementia by the service users themselves and staff, with post diagnostic support generally regarded as deficient and available activities tending to be tailored towards older people (Giebel et al, 2020). Including four younger people living with dementia, potentially challenges the positive core of AI to a greater extent but also strengthens the sharing of positively focussed narratives from this marginalised group.

2.4.2 Research process

The research process was designed to answer the research questions introduced in chapter 1:

- Can AI support people living with dementia to define a lived experience of ideal verbal positioning by others?
- Can the outcomes of an AI cycle with people living with dementia influence the verbal positioning of other groups in society?
- What factors influence the verbal positioning of people living with dementia by members of society aware of the AI outcome?

Four people living with dementia engaged in an AI workshop using the first three phase of the 4D approach. AI workshops may be conducted over a series of days, although it has been proposed that the four phases could also be worked through in a brief discussion during a lunch break (Cooperrider & Whitney, 2005). The workshop was designed to be completed over one or two days, depending on the needs of the participants. The first day was proposed to complete the Discovery and Dream phases, which would involve the group appreciating their positive stories and generating ideas for how the group considered the world might be. Due to the expectations on participants during these two phases, the next phase, Design, was proposed for the following day. Design would involve the filming of a video for participants to share their perceptions with the three discussion groups regarding how they would like the world to be, drawing on the previous two phases. A full day was allocated to Design, in foresight of any difficulties with filming and the intended structure of the film e.g. if a participant wanted the researcher to read a participant's contribution, if they did not want to appear on camera themselves, a script would have to be developed. Due to the innovative application of the 4D approach, the process detailed here would be open to change based on participant's needs, aligned to the democratic nature of AI.

Both the Discovery and Dream phases were completed in one day over a period of four hours. The group declined to wait for the following day to move into the Design phase and requested that the AI process continued. Two reasons were given by the group for continuing the workshop on the first day. The first reason was that the group stated that the first two phases had inspired their creativity and wanted to make the film whilst they felt empowered and motivated. Secondly, the group members were concerned that if the phase was left until the next day they may forget, due to their dementia, what they wanted to say in the film. One participant did ask to film their section of the recording on the following day, as he felt that he needed time to consider how he would present his thoughts during filming. The participants democratically agreed that three of them would complete the three phases during the one day session and one participant would complete the Design phase during the following day. All participants were present for the Design phase on the first day, when three participants completed the filming of their narrative. The fourth participant completed their filming later in the same week.

Delivery, as the phase where change is implemented, involved the presentation of the film to the three discussion groups and therefore did not require the presence of the people living with dementia. This represents the most significant innovation to the methodology as the AI process typically involves the same participants throughout the four phases. In this study, the generativity of the first three phases is being tested to produce an outcome to implement change in those outside of the initial AI group.

The Delivery phase was completed during the three discussion groups. Each group was provided with a pre-film case study with questions to encourage discussion about people living with dementia. The Delivery phase was executed as the film created by people living with dementia during Design was observed by the groups. A post-film case study with questions was then provided to each group. Both pre and post-film case study discussions were filmed for subsequent analysis. Groups took 20 to 30 minutes to discuss each case study, with filming stopped following the natural close of each group's discourse. The case studies were developed to encourage the participants to discuss people living with dementia. Both case studies were refined over several drafts and supervisory sessions so the information would be sufficient to inspire discourse but would not be clear enough to make any definite conclusions. Although the case studies revealed that the person being discussed had a diagnosis of dementia, the lack of information regarding the stage or sub-type of their dementia was deliberate. By denying this more detailed information, the case studies supported the participants to share their positioning of people living with dementia based on their existing assumptions, supporting the analysis to assess whether the film altered these assumptions and positions. The pre-film case study, about a person living with dementia named Beryl was:

Beryl has dementia.

She lives alone in a warden-controlled bungalow.
Beryl has a carer who visits her for ten minutes every morning to check that she has taken her tablets. This carer is paid for by Beryl's family who live in London and do not regularly visit her. Beryl is taking Donepezil (a medication for dementia) and is reviewed by the local memory service every nine to twelve months).

Beryl used to meet a friend in a town centre café but has been unable to meet her recently as the bus service has been reduced to only two buses a day and she lives six miles from the town centre. There is a small local shop half a mile away although this is down a steep hill.

Do you think that it is safe for Beryl to be living alone?

What do you think would help Beryl?

What do you think might happen to Beryl if she does not receive the help you have suggested?

Do you think that Beryl would benefit from attending a day centre?

What would Beryl do there?

The post-film case study, about a person living with dementia named Sally was:

Sally has dementia.

She lives with her husband who also has dementia. Neither are currently receiving support from either health or social services.

They have previously been in touch with a service for carers and have been given a telephone number to ring if they feel that they need help in the future.

Sally continues to drive although she now avoids long distance journeys but feels this is due to her own preference rather than a decline in her driving ability.

Sally never had any children and there are no other family members in the area. They both regularly attend church and until recently used to play bowls but stopped when Sally gave up her role as club treasurer.

Do you think that it is safe for Sally and her husband to be living together without support?

What do you think would help Sally?

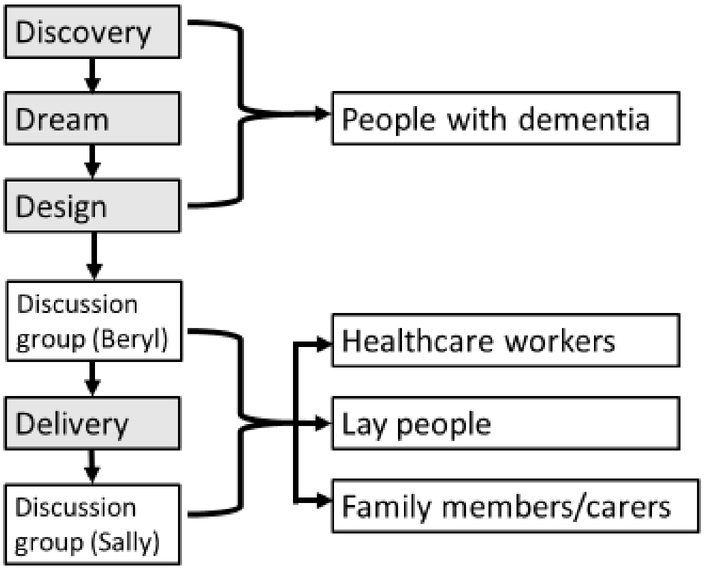
What do you think might happen to Sally if she does not receive the help you have suggested?

Do you think that Sally would benefit from attending a day centre?

What would Sally do there?

The framework for the study, illustrating the participant's relation to the AI phases and the discussion groups is presented in Figure 4.

Figure 4: The research process



Appreciative questions

Creating questions, which are both appreciative and generative is key to the AI methodology. Whilst the ability of the AI outcome to influence societal group's positioning of people living with dementia is the interest of this study, positioning theory was acknowledged when designing the AI questions as unfamiliar to non-theorists. Positioning theory was included in both the verbal information and information sheets for participants but the value of being 'positioned' was acknowledged as potentially obscure and confusing, if included in the affirmative questioning. Therefore, questions were developed for participants to discuss their positive historical experiences and envision their ideal concept of the future, without using the language of positioning theory. The researcher, as part of the democratic process, was able to discuss positioning as part of the 4D phases without negating the generative capacity of the participants.

The appreciative questions were:

Discovery

‘Think of a time, since your diagnosis of dementia, when you feel that you have been treated with dignity and respect during your conversations with other people.

What was happening or happened on that day that allowed this positive experience to happen?

What are the contributory factors?’

Dream

‘It is one year from now. You find that you and all other people living with dementia are always treated by others (both personally and in all other aspects of life) in a manner that you feel is appropriate to you.

What does this look like?

How do people talk to you or about you?

What is happening that is not happening at the current time?’

Design

‘Using what you have discovered and your vision of the ideal world, design what the ideal should look like.

Design how you would tell other people how you want the world to be?’

Delivery

This phase involved the Delivery of the film created during Design to the three discussion groups.

Each discussion group was presented with a case study prior to viewing the film. The case study included questions relating to the fictional person living with dementia described (Beryl). The case study was designed to encourage discourse about people living with dementia. The details in the case study were deliberately designed to encourage participants to discuss their assumptions about people living with dementia rather than provide substantial evidence for indisputable answers to the included questions.

Following this discussion the Delivery phase was actualised as the discussion group watched the film created during the Design phase. Following the viewing of the film, the group were asked to discuss another case study (Sally), which was designed using the same principles as the pre-film case study.

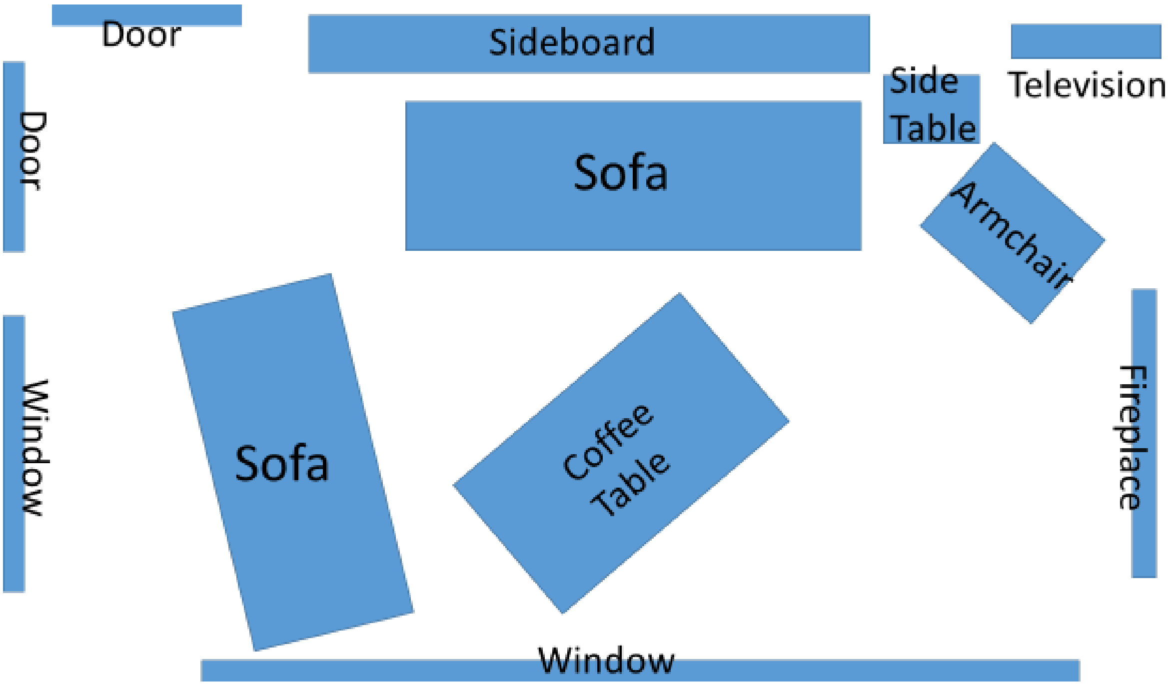
Data collection

Once the four participants had informally agreed to take part in the study it was necessary to arrange a location to conduct the research. The possibility of entering discussions with the proprietor of the public house was briefly discussed and I informed the group that I would make enquiries and make contact once we had a confirmed location. During the following week, one of the participant’s spouses contacted me using the telephone number on the information sheet and suggested that this complexity could be erased by completing the study at their house. They shared that their house was already familiar to the participants who had visited there before and they had a large conservatory where the study could be completed without any interruptions. I gratefully accepted this offer with the proviso that this location was acceptable to the other participants. We agreed a date and time and each participant or their spouse was approached by telephone to agree the suitability of the location and the dates. One participant was contacted directly to discuss and arrange the day of the study whilst the three other participants requested that the details of the days were arranged through their spouse. Although no objections were raised regarding the location of the study, it was necessary to complete a round of three telephone calls to confirm dates and times. The arranged dates were 11.09.2018 to complete Discovery and Dream and 12.09.2018 to complete Design. We agreed to meet at the house at 10.00am and set aside four hours on both days. Although it was unlikely that all this time would be required, this time was allocated due to the novel application of AI and the potential requirement for any breaks during the day.

Two participants were brought by car to the house for 10.00am by a relative and one drove to the house independently, arriving shortly before 10.00am. As they had all been to the house before, participants had not required any instructions to get to the location. Whilst the researcher brought refreshments for participants, the home owners had also arranged some further refreshments, which were available throughout the study period. One relative stayed in the house with the home owner spouse in a different room during the study. The other relative suggested that they would return in three hours but would go to the front of the house and socialise with the other relatives, as not to disturb the study. They also suggested that if the study was completed before they returned, they would be available to return earlier and left their telephone number.

The study was completed in the conservatory, which was a large room containing two sofas, a television on the wall, a fireplace, a coffee table, a small side table and one high armchair with wooden arms. A plan of the conservatory is presented in Figure 5.

Figure 5: Layout of the conservatory

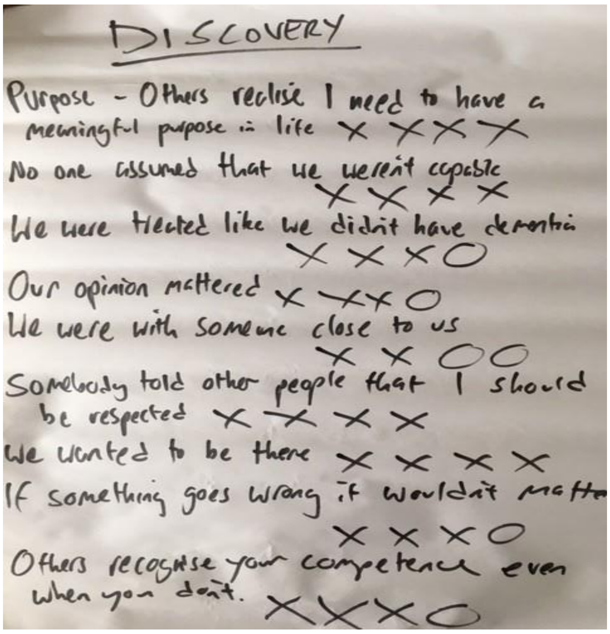


The size of the conservatory allowed the four participants and the researcher to engage comfortably, with the coffee table providing a working area when data was transferred to poster size paper during the Discovery and Dream phases.

On arrival the participants and relatives had some brief social engagement with each other and each participant discussed their understanding of the study with the researcher, revisited the study information and completed the written consent form. Once all four participants had completed the consent process and were located in the conservatory with the researcher, the Discovery phase was started.

Initially the participants were asked to share their positive narratives with each other in pairs. The offer was made to choose a partner for this part of the study although all four agreed that they would speak to the person that they were already sitting with on the sofa. Each participant was given ten minutes to discuss their positive narrative whilst the other member of their pair wrote down any factors that they thought had allowed this experience to happen (contributory factors). As one participant found the process of identifying a positive narrative difficult (see 4.2), the researcher supported the initial discussion to adjust the positive question and this supported the participant (with support from other participants) to share their positive narrative. This extended the proposed 20 minute exercise to 30 minutes. The group then joined together and shared their narratives again whilst all participants and the researcher attempted to identify the contributory factors. Once all four participants had shared their narratives, the contributory factors were added to poster sized paper with markers to indicate the number of occurrences of each contributory factor in the shared stories. Following the group discussion, any notes completed during the discussion in pairs were revisited to ensure that no contributory factors were missed. The contributory factor list and the occurrences for individual narratives was agreed as accurate by the four participants. This final group stage was completed in 30 minutes, meaning that the Discovery phase was completed in 60 minutes overall. A section of the contributory factor list created during Discovery is presented in Figure 6.

Figure 6: Contributory factors in Discovery (11.09.2018)



DISCOVERY

Purpose - Others realise I need to have a meaningful purpose in life X X X X

No one assumed that we weren't capable X X X X

We were treated like we didn't have dementia X X X O

Our opinion mattered X X X O

We were with someone close to us X X O O

Somebody told other people that I should be respected X X X X

We wanted to be there X X X X

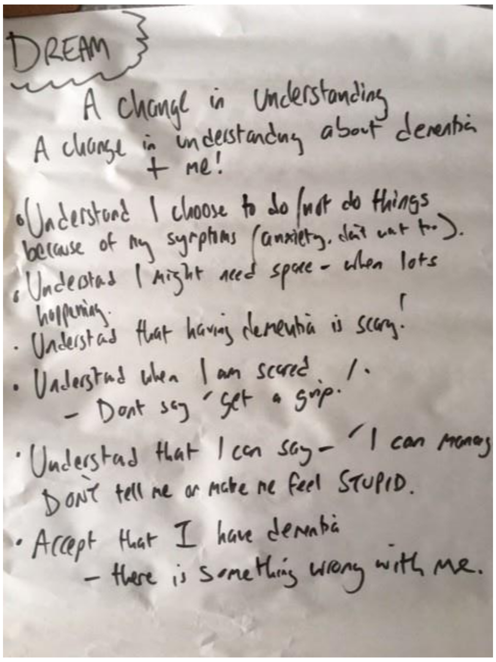
If something goes wrong it wouldn't matt

X X X O

Others recognise your competence even when you don't. X X X O

Although a break was offered prior to the Dream phase, this was declined by the participants who stated that this was not necessary due to refreshments being available during the study. The Dream phase included all four participants engaging as a group. As this phase encourages creativity, the conversation of the group moved between subjects quickly and the researcher scribed notes of the participant's descriptions of their ideal world whilst they were discussed. Following the discussion, the notes were discussed and the data was added to poster sized paper. Once the factors within the Dream had been viewed and agreed by the participants, they were supported to discuss the similarities between the factors they had developed and how these could be understood as a vision of their ideal world. The group were supported to thematically organise the data and this was illustrated on poster sized paper. The development of themes during the Dream phase was aligned to co-construction (Gergen, 1982) and the enhancement of participation and democratisation described by Cram (2010) when AI participants are encouraged to be actively involved in data analysis, alongside the researcher. Once the themes and the factors related to them had been added to the posters, each participant verified their accuracy. The Dream phase was completed in 75 minutes. One Dream phase poster developed during the inquiry is displayed in Figure 7.

Figure 7: The Dream (11.09.2018)



DREAM

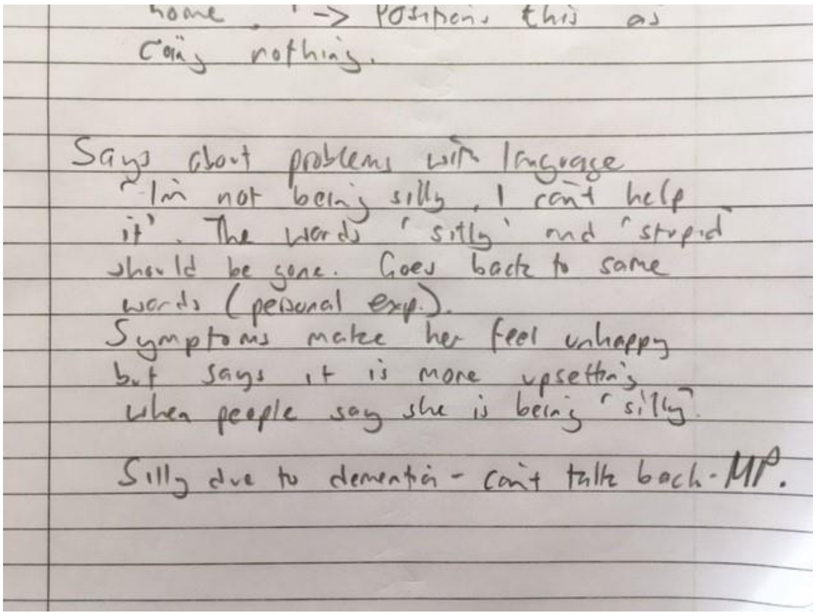
A change in understanding

A change in understanding about dementia
+ me!

- Understand I choose to do/not do things because of my symptoms (anxiety, don't want to).
- Understand I might need space – when lots happening.
- Understand that having dementia is scary.
- Understand when I am scared.
  - Dont say 'get a grip.'
- Understand that I can say – 'I can manage'
  DON'T tell me or make me feel STUPID.
- Accept that I have dementia
  - there is something wrong with me.

Field notes were also collected by the researcher during both the Discovery and Dream phases. An example of the field notes is displayed in Figure 8.

Figure 8: Field notes example (11.09.2018)



home.' -> positions this as
doing nothing.

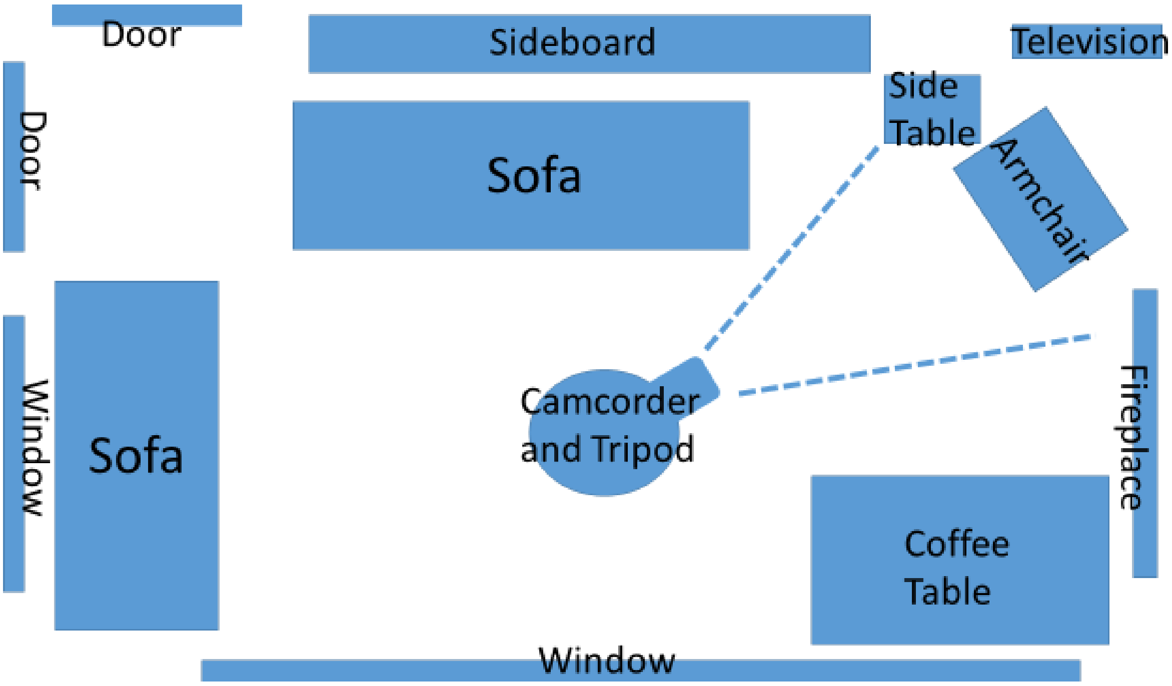
Says about problems with language
'I'm not being silly, I can't help
it'. The words 'silly' and 'stupid'
should be gone. Goes back to same
words (personal exp.).
Symptoms make her feel unhappy
but says it is more upsetting
when people say she is being 'silly'.

Silly due to dementia - can't talk back - MP.

Although a second day had been proposed for Design, the participants requested that they continued onto this phase on 11.09.2018. Although the first two phases had not required any filming equipment, the researcher had a camcorder and tripod to complete the Design phase with three participants on 11.09.2018. A break of 30 minutes was taken prior to entering the Design phase. This time was also used to check with the relatives whether there would be any concerns if the day ran over the previously agreed 14.00 finish time. The relative who had left the house was also now present and all three agreed that it would not be inconvenient if the study extended beyond 14.00 and the following day was cancelled. One participant requested that they would participate in discussions about Design on this day but would prefer to record their own contribution on another day (see section 4.4). Whilst Discovery and Dream had a very clear process with the outcome of posters to present the contributory factors and the ideal world, the outcomes of Design were not clear prior to completing the phase. The creation of a film to share with other groups had been included as part of the consent process although this did not indicate the design of the film. To explore and answer the questions embedded in the thesis it was necessary for the AI process to result in the creation of a film but the design of this film was led by the participants. I was aware that the participants could choose any design, which could lead to only their spoken voices or narratives (read by somebody outside the group) being included. This would also mean that the visual side of the film may have a degree of complexity (e.g. the inclusion of images or other videos with voice-over added) that I would struggle with technically. However, when deciding on the design of the film, the methods proposed by the participants were simple and ensured the narratives of each participant took precedence over any visual flourishes.

The participants agreed that the Discovery narratives were crucial to their film as sharing the ideal world was important but illustrating how this had already happened in their lives was crucial. Each participant took a turn in front of the camera and shared their Discovery narrative. Prior to filming, the four participants agreed which Dream theme or factor they would discuss during their filming period. To support this design, the poster detailing the chosen Dream theme or factor was held at eye level for the participant whilst they were filmed. The coffee table was moved to create space for the tripod and camcorder (see Figure 9) and each of the three participants were filmed in turn.

Figure 9: Rearranged conservatory for filming



The camcorder was the only recording device used and was stationary throughout the recording. The camcorder was arranged so that the participant was seen from the waist up and participants sat in the high armchair with wooden arms. From this angle, only the participant, the corner of the fireplace, the bottom of the television and part of the side table were visible on the film (see figure 10).

Figure 10: View of participants in conservatory during film (11.09.2018)

The first participant (Pauline) to complete the filming raised no concerns about the process but once in front of the camera admitted that they found it off-putting. They started to share their narrative but then stopped, saying that they had lost the thread of what they were saying. They then suggested that rather than turning the camcorder on and off during these pauses, the camcorder should continue to film and afterwards the researcher should remove any pauses or periods of silence. This was agreed with the other participants. Pauline was noticeably more relaxed when filming commenced and after describing their chosen factor in the ideal world, she stopped and said she was ready to say the same thing again on film. Pauline was made aware that the camcorder had already captured what she had said but if she wanted to re-film that section it would be possible. Pauline admitted she had forgotten the camcorder was on and was happy for the original version to be included. The second participant (Colin) had some difficulty recalling their Discovery narrative with the same detail as they had previously shared (see 4.2). They also requested that the content of the Dream factor poster was read to them before they shared this on the film. Once discussing the ideal world, Colin appeared more comfortable. The third participant (Sue) was initially quiet when speaking in front of the camera but grew louder as filming continued and was able to move from her Discovery and Dream narrative without difficulty.

The Design phase, including both the discussion of what the film would look like and the filming of three participants, was completed in 60 minutes. Once this phase was completed, we discussed watching the footage to ensure that each participant was happy with the content. Each participant watched their own footage. The participants and researcher agreed that during editing, no narrative data relating to the inquiry would be removed from the film. The participants agreed that because the Discovery narratives were integral to the film, they provided the title: ‘Four people. Four experiences’. They also agreed that each participant should be seen in the film in turn, with no narratives mixed together and each person should be introduced by a quote from their narrative displayed on the screen. They suggested that the researcher should choose a quote directly from the film.

The participants and their relatives were thanked and the relatives joined the group in the conservatory. The home owner spouse offered a hot drink to everyone before they left and all agreed to stay for this refreshment and social activity. During this period, the fourth participant (Gavin) asked if the researcher could visit them at their house during the week to complete their filming. This filming was completed on 14.09.2018. The participant was alone in the house and filming was completed in their lounge. The study process and consent were revisited with the participant having excellent recall of this and the previous phases. The supporting materials from the previous day were available for the participant although they did not require these. The camcorder was set up on the tripod and was pointed at the participant sitting on a sofa. The filming captured the participant from the waist up. Also visible was a window on the right hand side with the curtains closed (due to the glare of the sun) and a window with the curtains open at the back. Only the sky was visible from the open window. The researcher arrived at the house at 10.00am and filming was completed by 10.35am. The participant was relaxed and recalled their narratives without difficulty. Following the filming, the participant watched the film and spoke to the researcher about the two days, with the researcher leaving the house at 10.50am.

All discussion groups were filmed and then transcribed for analysis before and after the Delivery of the AI film. All data was held securely in an encrypted programme file on a Bangor University computer and a full back-up of the data was held on an encrypted external hard drive, which was held in a secure location.

Film production

The expected product from Design was a short film designed by people living with dementia and co-created by this group and the researcher. The people living with dementia would be responsible for the audio and visual content of the film, whilst the researcher would support the group to capture their vision. The researcher was responsible for editing the film but edits were based on the instructions of the people in the film. The production of a film is a creative activity, which was a key element of assessing the effectiveness of the AI process and the ability of the thesis to meet its aims and objectives. Creativity, however, has rarely been an attribute associated with people living with dementia (Camic et al, 2018) with suggestions that people living with dementia are generally less creative when attempting to create novel artistic products (Palmiero, Giacomo & Passafiume, 2012). The sub-type of dementia attributed to the person has also been indicated as a potential barrier or facilitator for artistic appreciation and creativity (Brotherhood et al, 2017). Whilst being involved in creative arts is recognised as potentially beneficial for people living with dementia, there has been little focus on the abilities of people living with dementia to engage co-creatively or to create products that are meaningful outside the act of creation (Camic et al, 2018; Bellass et al, 2018; Windle et al, 2018). Studies and activities have also typically positioned people living with dementia in a passive role with few opportunities to influence how they are conducted (Bellass et al, 2018).

The participation of people living with dementia in the creation of short films has tended to focus on autobiographical recollections (Calvert et al, 2019; Capstick, 2011; Ludwin & Capstick, 2015; Capstick & Ludwin, 2020). Autobiographies of people living with dementia in a housing with care facility have been used to soundtrack images of the past (Capstick & Ludwin, 2020). Participants were proposed to have full editorial control of the film-making process although only three of the ten participants were deemed to have capacity in relation to the study. The authors, whilst advocating for the full participation of people living with dementia in film creation, acknowledged that the outcome was more aligned to digital storytelling than a fully participatory film-making experience. ‘The Changing Face of Our Neighbourhoods’ is an autobiographical series of films, designed and co-produced by people living with dementia and their carers (Calvert et al, 2019). The films were created by interviewing participants on camera with the final edit only including the discourse of the participant. Green screen technology was used to include images behind the participant, relating to their reminiscence. The film positively included the long-term recollections of people living with dementia rather than exploring the deficit based focus on short-term memory, more typically the focus of dementia research. Whilst co-created films have generally focussed on autobiographies, co-created theatre productions have been developed to raise awareness of dementia (Jenkins, Keyes & Strange, 2016) with family members, including people living with dementia, producing vignettes that have subsequently been performed by trained actors.

The need to produce a film was clearly stipulated in the study information sheet and consent process. Until Design, however, there were no discussions about what the film would include or look like. Despite the researchers reservations about the possible complexities of producing a film, the design and content of the film was determined to be the product of the participants, in alignment with the principles of AI. The Design phase bridges Discovery and Dream, taking the best of what is and what could be (Cooperrider & Whitney, 2001). The participants embraced the phases of the process and agreed that the film would include the content from the previous two phases. The four participants chose to individually share their Discovery narrative and each chose an element from Dream to discuss on-screen. The discussion regarding the visual design was brief as the participants focussed on the information they wanted to share. Similar to the short autobiographical films (Calvert et al, 2019), the participants chose to sit and speak to the camera. However, the participants did not ask for questions to inform their contribution but went through a process of sharing their Discovery and then a vision of the ideal world. The Design phase on 11.09.2018 was completed in 60 minutes. This included a 20 minute conversation about the design of the film and the allocation of Dream factors for discussion. Pauline was filmed for 8 minutes and 53 seconds (8:53). Once edited, Pauline's discussion accounted for 6:23 of the final film. Colin was filmed for 10:00, which after editing, contributed 3:32 of the final film. Sue was filmed for 4:23, which after editing, contributed 3:12 of the final film.

Each participant watched their own contribution after filming on the camcorder's internal screen. The researcher suggested that the group could watch each narrative, linking the camcorder to the television, but one participant did not want to view themselves on the larger screen. All four participants then agreed to watch their individual films only. The participants and researcher agreed that no relevant discourse from the film would be removed for the final edit. Editing was agreed for any pauses in the film when the person was considering what to say or when the researcher was asked and replied to any questions during the process. Colin also indicated that he had spoken for a considerable length of time about the RAF and asked for any material, not directly related to his Discovery narrative to be removed. To separate each narrative, the participants requested that a quote from each participant was placed on the screen prior to their narrative. The researcher suggested that the participants could choose their own quotes but the participants stated that they wanted the researcher to identify these elements. The quotes and how they were displayed in the film are discussed in 4.4. The visual presentation of the narratives is illustrated in the Data Collection section of this chapter.

Design was completed on 14.09.2018 with Gavin. This included a 20 minute discussion regarding the filming and the location of the camera, as well as revisiting the content of the previous phases. Gavin was filmed for 5:01, which after editing, contributed 3:58 of the final film. Gavin watched his individual narrative on the screen and reiterated his request for pauses to be edited out of the final film.

Editing was completed by the researcher using Windows Movie Maker. Each narrative was uploaded to the editing software and was slowly edited to remove the areas indicated by the participants. Editing involved repeatedly watching the same sections of film, which provided a familiarity with the material. Following the editing of each narrative, as instructed by the participants, a quote was added to the screen prior to each participant talking. The completed film was edited over the course of one day. The final film had a running time of 17:05.

Unfortunately, it is not possible to share the completed film outside of its consented use by the four people living with dementia. The participants wanted to use their real names in the video but only with the acknowledgement that the film was being shared with the three societal groups detailed in the study information and not with anyone outside the study. Movements to remove anonymity in research to enhance public awareness of the creative abilities of people living with dementia (Bellass et al, 2018) are vital in challenging the power relationships between researchers and participants. However, the desire for anonymity and the power to remove consent if this anonymity is not preserved, must be a fundamental right in research with people living with dementia. Although the participants are presented with pseudonyms in the thesis, this does not prevent the discursive content of the film being directly illustrated in the findings and can be observed throughout chapter 5.

2.4.3 Data Analysis

In this section, the approach taken to analyse the data will be addressed. The analysis of the data was crucial to the outcomes of the research and will be demonstrated as having been achieved through a rigorous process.

Rigor

Qualitative research and analysis has been criticised for potentially lacking rigor, being dependent on the skills of the researcher and prone to bias due to the researcher’s influence (Anderson, 2010). Small sample sizes and a lack of generalisability to larger populations have also been cited as potential weaknesses of qualitative approaches (Lincoln & Guba, 1985). Numerous suggestions have been made to enhance the rigor in qualitative studies. In this thesis, the methods advocated by Green and Thorogood (2004) to strengthen the transparency, reliability and validity of analysis in interpretive/constructivist studies have informed the analysis and its illustration. The three feature identified as hallmarks of rigorous qualitative research are: transparency, reliability and validity (George & Thorogood, 2004).

Member checking has been cited as a mechanism to enhance rigor in qualitative research (Lincoln & Guba, 1985) as it provides a way to ensure that what the researcher constructs from the qualitative data is accepted as authentic by participants (Candela, 2019). Participants did raise concerns regarding their ability to recall data from the AI phases if they did not complete the first three phases in the same day, suggesting potential difficulties with member checking if data was revisited after a significant length of time. However, the AI phases supported member checking throughout the three phases of the initial inquiry during data collection. The narratives in Discovery were analysed for contributory factors, which were indicators of what allowed positive positioning to occur. These contributory factors were member checked by participants to agree whether they occurred in their shared narrative. Only contributory factors, which were authenticated by participants were included in the findings. The Dream was initially scribed by the researcher, whilst listening to the discourse of the participants. Following the discourse, themes concerning the ideal world were co-created by the researcher and participants. The visual display of the Dream themes and the factors associated with these on posters supported the four participants to member check their accuracy. Design included the creation of a film. The content of the film was member checked in its unedited form and the participants indicated the sections that were edited out to ensure the film was an accurate reflection of their Design. Delivery led to the analysis of discourse by three societal groups. The final group discourse was captured on 04.12.2019, which was 15 months after the initial AI workshop with people living with dementia. The in depth analysis of this discourse meant that the rough findings were only available from March 2020. Due to the time that had passed and after listening to the concerns raised by the participants living with dementia regarding their ability to recall the content of the phases over a much shorter period of time, member checking was not attempted for this phase. Although the film from Design could have potentially been used to support member checking by this group, the rigor of this approach would be questionable as interpretations are likely to change over time (Birt et al, 2016).

Transparency

This relates to the clarity of description given to the analytical process. Weiland (2003) has argued that it is the instability of qualitative inquiry and analysis that attracts researchers to the approach and suggests having rigorous methodological guidance could be counterproductive as it risks narrowing exploration. This lack of transparency could also explain the intolerance of some quantitative researchers towards qualitative approaches, as innovative and flexible research methods are frowned upon due to a lack of transparency. The analytical approach must be explicit if transparency is to be achieved. The illustration of findings should also illustrate how they arrived through the analysed data. A description of the analytical process is described in this chapter, whilst the data analysis is also clearly signposted during the findings chapters in the thesis.

Accounting for the role of the researcher is required to maintain transparency (George & Thorogood, 2004). The researcher's role in AI has been discussed earlier in this chapter, taking a democratic role within the 4D approach without altering the narrative data of participants. The thematic analysis during the 4D approach shared by the researcher and participants is crucial to the methodology and must be acknowledge for transparency.

Reliability

This concerns whether the interpretation of data could be repeated to achieve the same outcomes. When using an inductive approach there is less expectation that two researchers would achieve the exact same results, due to the individual researcher's knowledge, inquiry of interest and theoretical approach (Green & Thorogood, 2004). Reliability, however, remains crucial and a researcher should be able to demonstrate how the data has credibly informed their findings, as well as how themes have been developed from the data (Green & Thorogood, 2004). Reliability is dependent on accurate transcriptions, which were actualised by the researcher completing all transcripts and using these in conjunction with the video recordings during data analysis. Having both sets of data was key to the reliability of the analysis as the meaning of discourse could be misinterpreted when using the transcripts in isolation.

Field notes were complimented by the methodology, as the narratives and visions shared by the participants during AI informed the ongoing process of the approach. This allowed the field notes to be checked for accuracy, as well as being expanded, by participants during the research process. Equally, participants were able to view their contributions to the AI film immediately after recording, ensuring that the data collected was befitting their Design and in line with the democratic process.

Validity

Whilst qualitative data is open to multiple readings, the researcher must be able to assure the credibility of their analysis. Choosing to analyse data, which provides the most interesting or outlandish results has been identified as a common issue in the validity of qualitative analysis (George & Thorogood, 2004). In the AI analysis, all the contributory factors from Discovery were created and agreed by the participants and in chapter four, will be clearly illustrated to inform the themes developed. When analysing the positions allocated to people living with dementia during the discussion groups, all discourse was analysed and all thematically relevant positions were entered into the Balancing Framework. The process of analysis using the Balancing Framework is described in chapter 5.

George and Thorogood (2004) also highlight the requirement for researchers to look for deviant cases, were analysis does not show what the researcher wants or expects. The analysis of positions in this thesis shows a variance in results across the three discussion groups and the individual within the groups, allowing the inclusion of deviant results. The narrative of the findings should not only describe the results but also include raw data extracts (Braun & Clarke, 2006) and excerpts of the AI and discussion groups transcripts are included throughout the findings chapters. Validity is upheld through saturation (George & Thorogood, 2004) and both thematic and positioning theory analysis were repeatedly analysed to ratify the results. The three discussion groups provided a natural comparison between data sets, illustrating a further hallmark of qualitative validity (George & Thorogood, 2004). External validity questions whether the findings of the research are generalizable to larger populations than those included in the study. Allowing other researchers to analyse data from the study to ascertain if they make the same judgements has been advocated as a mechanism to scrutinise external validity (Bergin, 2018). Although data analysis was shared with the PhD supervisory team, it should be observed that this study does not suggest that all its findings are generalizable. There is no suggestion that the four people living with dementia in the AI workshops and their vision of the ideal world, represent all people living with dementia. Equally, the discussion groups do not represent all healthcare workers, lay people and family members/carers. The exploration of AI as a valid methodology for people living with dementia, and other minority groups, to influence change in others is generalizable with the process explored in this chapter and the subsequent findings chapters informing the external validity of this outcome.

Analytical approaches

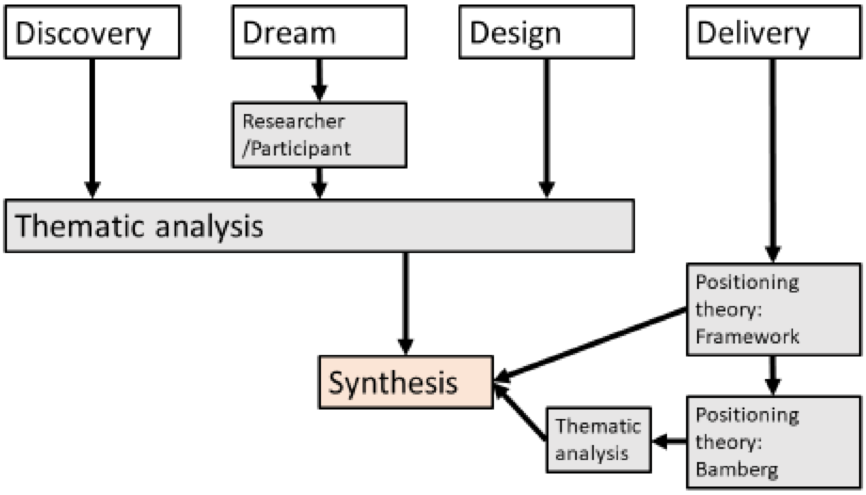
Analysis occurred during the inquiry, following the collection of data in the AI group and following the completion of the discussion groups. The analysis was multi-layered through multiple components. As an analysis of the AI methodology, the aim was to determine whether AI is a valid approach to support people living with dementia to generate ideas about their ideal world regarding the subject of inquiry, understand what this ideal world would be and support people living with dementia to create a tool to inform other social groups about their desires. Whilst, these three aims were observably achieved through the completion of the AI 4D approach, the process of how the approach was tailored to suit the individuals in the group was incorporated into the analysis. The aims of the overall analysis were to understand whether the viewing of the AI outcome, designed by people living with dementia, influenced the verbal positions allocated by other social group members, to understand if the film, created by people living with dementia through AI, was an effective mechanism to socially influence other groups and to clarify whether the positioning of people living with dementia by other groups was more closely aligned to the ideal world, envisioned in Dream, following the Delivery of the AI film. A further aim of the analysis was then to understand the personal factors, which guide the susceptibility of discussion group members to being influenced of the AI film, when positioning people living with dementia. The initial analysis was completed during the AI workshop, with both the researcher and the participants involved in the theming of data from the Dream phase.

Three approaches were used during data analysis. Thematic analysis was chosen as an inductive mechanism to support the data to inform original analysis rather than attempt to add data to pre-existing frameworks. The Balancing Framework was developed as a novel mechanism for positioning theory analysis to assess the effect of the AI outcome on discourse. Finally, Bamberg's (1997) levels was chosen as the clearest positioning theory model to consider how the speaker positions themselves during discourse. The three approaches were:

1. Thematic analysis
2. Positioning theory: Balancing Framework
3. Positioning theory: Bamberg's (1997) levels

Theming during the Dream phase was completed during the AI workshop by the researcher and the participants. Thematic analysis, using Braun and Clarke's (2006) approach, was used to draw together the findings from Discovery, Dream and Design. The outcome of the thematic analysis included the development of a Balancing Framework, which allowed positioning analysis to be undertaken on the discourse of the discussion groups to ascertain whether there had been a movement in their allocated positions of people living with dementia, following observation of the AI film, which was aligned to the desires of the AI group. Positioning theory analysis was then undertaken using the outcomes of the Balancing Framework analysis and the discourse during the discussion groups to understand the influences on individuals within the discussion groups, when allocating positions to people living with dementia following the observation of the AI film. This analysis was then subject to a further thematic analysis to enhance the generalisability of the findings.
Figure 11 visually presents the AI phases and the method of data analysis applied.

Figure 11: Analytical approaches within phases of the 4D cycle



Analysis 1: Thematic analysis

To conduct the thematic analysis, the approach developed by Braun and Clarke (2006), and reviewed by Nowell et al (2017), was followed. The approach was developed to increase trust and rigor in qualitative analysis. The six stages, which are not always approached linearly, are described as:

1. Familiarising yourself with the data.
2. Generating initial codes.
3. Searching for themes.
4. Reviewing potential themes.
5. Defining and naming themes.
6. Producing the report.

The application of the stages to develop the themes and sub-themes described in the findings of chapter 5 will now be described. As the defining and naming of themes was completed within the process of the first four stages, only these earlier stages are independently described in the thesis.
A thematic analysis was also applied to identify positioning identities. This is signposted in the analysis design for Positioning theory: Bamberg's (1997) levels, whilst the findings in chapter 7 illustrate how the analysis was completed.

Familiarising yourself with the data

The analysis of the first three AI phases was drawn from the field notes of the narratives and 16 contributory factors identified during Discovery, the 31 factors identified and thematically allocated by participants and the researcher in Dream, the corresponding field notes and the film created by the AI group during Design. As I had independently facilitated the AI workshop, including the real-time analysis of the Dream with the participants, I already had a good level of familiarity with the data. All the collected raw data was archived as suggested by Nowell et al (2017) as a means to ensure an audit trail and to review the later analysis. The archive also provided a degree of much needed organisation as the format of the data sets was varied and required careful appreciation when analysed independently and as a set of overall data. My active involvement in the data gathering determined a pre-existing familiarity with the data but having the sets of data archived into smaller sections, allowed me to become familiar with individual data sets, allowing an insight into the phases of the approach, which was not possible during the active workshop.

The film created during Design, was also familiar due to my role as the camera operator. The participants had reviewed the footage following the recording and requested that sections when they had stopped talking and were thinking about what to say next were edited out. I had little experience with editing video footage but did this using Windows Movie Maker. Although this editing was required to finalise the Design phase, the process was invaluable regarding the familiarity it provided to the material.

As proposed by the analytical model, I engaged in re-reading and re-watching the collected data. During this early period, as suggested by Braun and Clarke (2006) I made notes when I observed outcomes of interest, which were subsequently used to inform coding and theming during later stages of the analysis. Considering how immersed I was in the process, I was also aware that my own involvement in collecting the data could bias my understanding and subsequent coding. This is addressed in the following stage, as a proposed deductive analysis was rejected due to its potential bias and misrepresentation of the collected data.

Generating initial codes

The familiarity I had accrued through the live workshop and the subsequent reading and viewing of the data collected provided a solid foundation for coding. The explicit descriptions in the contributory and Dream factors also provided a backbone to the coding of the transcript from the AI film. During the first attempts at coding I applied the results of the scoping review, which had been previously completed as part of this thesis to understand the verbal positions allocated to people living with dementia in the literature, to create a codebook. The codebook was developed as there was evidence that deductive approaches to coding, built upon previous literature concerning similar inquiries, enhanced the credibility of coding (Yukhymenko et al, 2014). However, although codes were allocated, the voices of the people living with dementia in the AI group were being lost as the codes developed from the literature dictated the meaning of the data, rather than the data informing the codes.

Coding was restarted as an inductive exercise with the initial deductive coding kept within a reflexive journal, which was revisited following periods of coding and theming. This allowed the scoping review to be present in the mind of the researcher during coding, without corrupting the coding process. The failure of deductive coding, further informed the importance of the participant narratives and the requirement to be immersed in the data, informing the decision to forego electronic data management software to keep the narratives at the forefront of the study.

The first stage of coding was attached to the contributory factors from Discovery. As these factors had been drawn from larger narratives during the AI process, there was an opportunity to observe factors as codes but having developed a familiarity with the data, there was evidence of overlapping codes regarding their meaning and context.

The second stage was the coding of the Discovery narratives. These were the hand written field notes, which had been used during the AI workshop to develop contributory factors and had been confirmed as accurately recorded by the group during the Discovery phase. Whilst these narratives had led to the development of the contributory factors, which had already passed through one round of coding, they provided the contextual data for how the factors developed.

The third stage of coding involved the Dream themes and factors, which had both been developed by the participants and researcher during the AI Dream phase.

Stage one and two coding had involved the first phase of AI but this next phase of coding was reassuring as the codes developed over the earlier stages were applicable to the new data.

The fourth stage was the coding of the AI film transcript created during the Design phase. Both the written transcript and the film were used during coding, although once coding was ready to begin, I had a good familiarity with the film following the workshop and editing processes. As the earlier two phases had informed the creation of the AI film, a risk existed that if coding was radically different in this phase it would be challenging to assess the positioning data from the forthcoming discussion groups against conflicting data within the AI phases. Due to my familiarity with the data, I was not overly concerned by this risk as I felt, both during the workshop and the reading/viewing of the data, that participants had developed their answers to the affirmative questions during AI by building on each subsequent phase.

Following, this first round of coding, the same process was completed again with the developed codes arranged in a codebook and data observed without the presence of initial code markings.

Searching for themes

Once the initial coding process had been completed, the identification of themes was started through a process of 'chunking' and 'displaying' (Crabtree & Miller, 1999 p.170). Chunking refers to examining related sections of text together, whilst displaying refers to mapping connections between the data. Due to the varying format of the data, both approaches were useful mechanisms to observe the content of the data within codes and the connections between the data within the AI phases. The data, as titles, was placed on post-it notes and posted on a display wall, allowing the connections to be viewed more clearly.

A crucial result of observing the codes in this visual format was a thematic bifurcation as data was observed to belong in two contexts. The larger context directly related to the aims of the thesis, through codes and data which related to the positioning of people living with dementia by other members of society. A second, smaller theme emerged regarding the experience of being a person living with dementia who is allocated positions by other members of society and the response to this form of discourse. This second theme had been established in the Dream themes developed by the participants and researcher but had been initially regarded as a deviant result but the formal analysis observed a similar presence in the data collected during the other AI phases. As the findings of a rigorous thematic analysis should imply how themes were developed, the content of these themes is not discussed here but is clearly addressed in chapters 4 and 5.

As the larger theme was driven by the understanding of what constituted preferable positioning, variance within the narratives initially disrupted theming. Revisiting Braun and Clarke's (2006) template informed the collapsing of some initial codes to understand the larger context of being positioned within a theme, rather than only observing for preferable coding.

This approach provided a triadic approach to the theming, with the established themes of positions allocated by others and the experience of being positioned joined by a theme considering the negative examples of positioning. Whilst AI, demands an affirmative approach, it does not deny the negative experience and although the affirmative questions had been built to understand the experience and desires of being positively positioned, substantial codes informed the opposite experience. This theming proved crucial when developing the Balancing Framework, as a means to analyse the discourse of the discussion group. Overlapping data within themes was observed, with ideals of positive, equally informing the negative experience. Although, it is not typical practice to include results in this section, this example from the Dream factors and its connection to the narrative in Design simply and clearly illustrates the connections between the preferable position and the negative experience. The Dream factor, an illustration of what the world would ideally be like, included:

> I can say that I can or cannot manage to do something without being made to feel stupid or worthless

A connection to this factor is shared by Sue during the AI film from Design:

> *'If you're upset or you find it hard to work something out, or you've not understood what they've said and you ask them again, they'll come out with 'oh, you're being silly, I've told you that'. The other one is 'stupid', 'don't be stupid'. (Sue)*

Following the completion of the three thematic areas, the results of the negative theme and the positioning theme were comparatively analysed, allowing the negative and positive codes and narratives to be merged into one thematic area.
As this process had developed, themes within the two thematic areas had already developed. Although these themes had arrived inductively, the allocation of contributory factors within different thematic areas informed a deductive shaping of these themes. On recognising the value of the contributory factors as the connection between the other areas of data I did not attempt to move away from this more deductive process as, unlike when attempting to code with the scoping review results, the data was travelling within the factors, rather than being forced into them. The conceptualisation of the factors as descriptors of positive experience had also been developed by the participants and attempting to reconceptualise these, would have pushed the results away from the lived experience of the people living with dementia, resulting in both a practically and academically redundant exercise. Through the analysis the contributory factors were reconfigured into eight sub-themes within four thematic areas, located within the overall concept of the position. The experience of being allocated positions was refined into three themes with six sub-themes, with the contributory factors realigned again to the outcomes of the thematic analysis.

Reviewing potential themes

Once the themes and sub-themes had been allocated, descriptors were allocated to provide a clear understanding of their meaning. As the theming process had been under constant review with ongoing re-coding and theming during the analysis, the completion of theming triggered a review, returning to the uncoded data. The application of the contributory factors to conceptualise the sub-themes demanded a further comparative analysis with the Dream themes and factors developed during the AI process. As the latter was an unfiltered thematic analysis completed during the AI Dream phase, it was crucial that it could be cleanly applied to the themes and sub-themes developed in this formal analysis. The allocation of Dream factors was cleanly applied to the developed sub-themes. This application was paramount in the testing of the Balancing Framework as a positioning analysis tool prior to its use with the discussion group data.

During the review it was apparent that although the data set was relatively small, the AI process had generated considerable insight to inform the thematic analysis. Whilst the affirmative questions during the AI workshop had aimed to understand the content of positioning, the development of three themes and six sub-themes regarding the experience of being allocated positions was an unforeseen outcome. The inductive approach towards the data, allowed these themes and sub-themes to be developed, which would not have occurred if I had remained beholden to the results of the scoping review, and proved crucial to the overall synthesis of this thesis.

The justification for the themes developed during analysis are clearly illustrated in chapters 4 and 5, as their alignment to the data is explored. The themes and sub-themes were further reviewed through the creation of the Balancing Framework and its successful analysis of positioning during the discussion groups.

Analysis 2: Positioning theory: Balancing Framework

The development and application of the Balancing Framework, although methodologically part of the analysis in the thesis, was informed by the findings during the study and is described in chapter 5.

For clarity, it is noted here that the Balancing Framework was used to assess discourse from the discussion groups, which could be allocated into the themes identified during the thematic analysis. The Balancing Framework was used to assess whether the allocated position(s) met the requirements of positive positioning as described by the people living with dementia during the AI workshop. An analysis of positions was completed during the first discussion (Beryl's case study) and the following discussion (Sally's case study), to analyse whether their positioning moved within the framework following the observation of the AI film. The results of the Balancing Framework analysis are explored in chapters 6 and 7.

The videos of the discussion groups and the transcripts of the videos were both used during the analysis. The analysis was repeated and reviewed, similar to the earlier thematic analysis to ensure the consistent use of the framework.

Overall, transcripts included 30,694 words and 637 positions were allocated to the Balancing Framework analysis.

A total of 58 words were removed from the analysis, which were all located in the same discourse during the healthcare worker group discussion. This part of the discourse was removed as, during analysis, the researcher's question to the group was considered too leading and although the discourse could have been entered into the Balancing Framework, its collection would have deviated from the methods used in the discussion groups overall.

Analysis 3: Positioning theory: Bamberg's (1997) levels

Level 1

The results of the Balancing Framework analysis alongside the discussion group transcripts and allocated positions were applied to the positioning analysis using Bamberg's (1997) methodology. The Balancing Framework analysis established whether there had been a change in allocated positions within the groups following the AI outcome whilst this analysis aimed to illuminate how positioning by individuals and groups was diversely influenced.

The first level analysis examined how characters were constructed within the discourse. The discourse of all three groups was primarily concerned with the case studies and therefore people living with dementia were the central characters in the majority of storylines. As these positions had already been analysed in the Balancing Framework, the outcomes illustrated the individual characterisations constructed by the individual participants. Data was also removed from the transcripts when positioning of people living with dementia did not occur, which included evidence of in-group positioning. Whilst the discourse regarding people living with dementia required further level 2 analysis to understand how the participant's positioned themselves and others in the group, there were also some clear examples of in-group positioning. The narratives regarding these positions were analysed within their storylines. One clear example was observed in the healthcare worker group when one participant was asked to physically move from the group due to a disagreement over their positioning of people living with dementia following the AI film. These explicit examples of in-group positioning occurred infrequently in the discourse.

The analysis of participant's discursive power was attempted by mapping the status of the participants to their discourse. The relational influence of power was initially classified using Max Weber's (1864-1924) (Gerth, Mills, & Turner, 2013) three-component theory of stratification. Traditional authority was observed within the healthcare worker group, through the senior members of staff whilst a family member, also held a managerial position within the workplace. However, when attempting to identify participants with charismatic authority, the variety within the discourse could not be reasonably analysed using the three components. This analysis was developed further in level 2

Level 2

This second level of analysis explores how the positioner attempts to position themselves. Whilst the in-group positions allowed a brief analysis, the small sample size was insufficient to offer an analysis beyond the isolated storylines. Allocated positions to people living with dementia, however, allowed for a further analysis of in-group communication.

The total number of 637 positions, observed within their storylines, dictated whether an individual altered their positioning following the AI outcome. Further analysis of these positions confirmed that there had been a total of 123 attempted 2nd order positions, when an existing position was challenged. There was a total of 195 confirm positions, when allocated positions were verbally agreed with by another participant and a total of 14 strengthen positions, when a participant continued to state their position despite the lack of confirmation or 2nd ordering by other group members. Mapping these positioning behaviours allowed for an overall analysis of positioners who offered more positive or negative 2nd order positions. The 2nd order analysis also illustrated whether participants challenged these 2nd orders depending on their positional value and the person communicating them.

Confirm positions were segments of discourse when a participant agreed with a previously allocated position. In some instances, the confirm position could be analysed as an isolated piece of discourse, incorporating the full meaning of the previously allocated position. A confirm position was also recorded when a participant offered a confirmatory or contradictory exclamation to an allocated position. These exclamations would be meaningless if analysed in isolation but within the storyline allowed the analysis to understand, which positions were agreed by larger members of the group and crucially, for this part of the analysis, illustrated the discursive relationships between group members. Similarly, strengthen positions, whilst few, also illustrated the positioners who would continue to stand by their allocated position despite receiving no discursive response from their peers. This approach allowed a statistical overview of positioning behaviour whilst the 2nd order, confirm and strengthen positions were taken from the transcripts and mapped between participants. This analysis provided a skeleton of relationships within the groups with discursive allies and leaders identified through these positional acts. Returning to Weber's three components of power, a similar analysis was attempted as described in level 1. The analysis revealed that rather than a clear definition between traditional and charismatic authority, experience was the focus of discursive power. The positions were analysed again, alongside the existing status of the participants, to record the positioning values, behaviours and storylines aligned to their experiences. These experiences as influencers are explored in chapter 6.

Level 3

The final part of the analysis considers the identity of the positioner, exploring how the allocated positions let the positioner answer the question 'Who am I?' (Bamberg, 1997 p.337). The analysed data between the two case study groups displayed the shifts in allocated positioning values and behaviours in the participants. Level 1 and 2 analysis had identified experiences as influencers on these allocations and behaviours. However, the natural group structure meant that participants had shared experiences but differed in their positioning behaviour. The examples from the transcripts of positioning behaviours were analysed from Bamberg's (1997) recommendation, by considering how the person wanted to be understood. This data was aligned to the results from the previous levels and subject to a thematic analysis using Braun and Clarke's (2006) model to identify five conceptual positioning identities. To review the positioning identity themes (part four of the framework) chunks of transcripts were analysed as storylines to assess whether the positioning identities could be identified within. The transcripts and positioning behaviour analysis were then analysed to observe the dominant behaviours of the participants. As suggested by Bamberg (1997), the identities shared during positioning only exist within the current storyline and that ephemerality was observed during the analysis. However, the analysis did allow the allocation of participants to their most commonly observed identity.

The three level analysis was collated to the outcomes of the analysis within the Balancing Framework and the AI in the development of the synthesised frameworks in chapter 8.

2.5 Summary

The first part of the chapter set out the AI research methodology, considering its development and application through the 4D approach. Positioning theory was introduced as the subject of change and natural discussion groups were explored as a means to explore positioning theory within pre-existing relationship discourses. The paradigmatic congruence between the approaches was established.

The research processes were described, including the innovative application of the 4D approach of AI with one group moving through the first three phases. Three social groups enter the final phase of Delivery, when the outcome of the three previous phases is delivered to them as a transformational influence.

The approaches used for data analysis were explored. Thematic analysis provided a clarity to the outcomes of the first three AI phases, allowing a vision of the ideal world to be themed by the participants and researcher during the workshop and the later development of an analytical tool based upon the thematic outcomes of the AI. The data analysis from the natural discussion groups allowed the question of whether the AI outcome could influence the positions allocated by others, to be answered clearly and affirmatively. The depth of analysis also supported the identification of positioning identities using Bamberg's (1997) levels.
The scoping review, which follows this chapter, establishes the current verbal positions allocated to people living with dementia as displayed in the literature, justifying the AI approach to change to this subject. The findings informed by the data analysis are then presented in chapters 4 to 7.

Chapter 3

Scoping Review of positions allocated to people living with dementia in literature

3.0 Introduction

This chapter describes the process and outcomes of a modified scoping review to justify the requirement to challenge the positioning of people living with dementia by other members of society and to understand whether the concept of 'ideal' positioning has been explored previously. The findings indicate that there are considerable differences between how people living with dementia position themselves and how they are positioned by others, whilst research indicating 'ideal' positioning is limited. Five conceptual themes were identified, using thematic analysis (Braun & Clarke, 2006) which encapsulate the dominate contexts of positions observed in the literature. These five themes are:

- Societal standing
- Practical ability
- Internal values
- An evolving self
- Control over life

The scoping review concludes with a justification for the empirical research in this thesis.

3.1 Rationale for scoping review methodology

To justify the research aims and objectives it is necessary to understand what the available literature illustrates regarding the current understanding of verbal positions relating to people living with dementia. The approach chosen to review the literature was a scoping review. The scoping review framework used for this review was developed using the methodology as outlined by Arksey and O'Malley (2005) with consideration of the recommendations provided by Levac, Colquhoun and O'Brien (2010).

The current literature concerning the protocols and purposes of scoping reviews supported the use of this review methodology. A common purpose of a scoping review is to identify gaps in evidence for future research projects (Tricco et al., 2016) whilst scoping reviews have also been acknowledged as a tool that allows a topic to be understood overall at PhD level (Peterson et al., 2017). A scoping review has the potential to provide a comprehensive overview of a broad topic when the literature is vast and diverse (Arksey & O'Malley, 2005; Pham et al., 2014) and can provide an evidence base prior to the establishment of practice guidelines (Peterson et al., 2017). Arksey and O'Malley (2005) also considered that a scoping review could be completed to identify gaps in research, to summarise research findings and to understand the breadth and nature of research activity in a particular field although the outcomes would be dictated by the purpose of the scoping review itself.

Although systematic reviews are established as a detailed and comprehensive methodology to appraise and synthesise studies on a particular topic (Uman, 2011) this would have been an impractical approach to the literature review in the context of this thesis. The question being asked of the review, concerning the verbal positioning of dementia, is not necessarily linked to a specific intervention or topic and therefore a systematic review would not provide the breadth of information required, Typically a systematic review aims to answer a specific question, often through specific forms of study or literature, whilst a scoping review allows a broader approach to be used through both the method used to map the literature and through a less specific research question (Peters et al., 2015). Unlike systematic reviews, scoping reviews are not created to assess the quality of the literature included (Arksey & O'Malley, 2005). This has led to criticism of the scoping review methodology by authors who have claimed that due to accepting literature without assessing its quality, the review is less rigorous than a systematic review (Levac et al., 2010). Others have argued, however, that the extent of literature used in the review results in scoping reviews having comparable rigour to systematic reviews (Liu et al., 2010). Rather than review the merits or otherwise of either methodology it is perhaps more practical to understand that the scoping review was borne out of a need for a different methodological stance to literature review, as a mechanism to gain and review literature in a manner that is not possible under the strict processes of a systematic review. There are areas of complex literature that have yet to be comprehensively reviewed and in these circumstances a scoping review would be the compatible methodology (Peters et al., 2015). The potential exists for a significantly greater number of methodologies and studies to be included in a scoping review in comparison to systematic review. A scoping review may act as a precursor to a full systematic review but this does not mean that the former is inferior. We should accept that a scoping review is a different entity to a systematic review (Brien, Lorenzetti, Lewis, Kennedy, & Ghali, 2010) or there would be little purpose in the two methodologies co-existing.

As the review's purpose was to identify actual examples of verbal positioning in the literature the use of a scoping methodology did not require significant debate as a systematic review would not provide the information required. There is no clear alternative methodology to use when examining diverse literature (Anderson, Allen, Peckham, & Goodwin, 2008). Although several definitions of what a scoping review or study is have been recorded, Daudt, Van Mossel and Scott's (2013) definition is possibly the most closely aligned to the aims of this thesis:

'Scoping studies aim to map the literature on a particular topic or research area and provide an opportunity to identify key concepts: gaps in the research; and types and sources of evidence to inform practice, policy making and research' (Daudt, Van Mossel & Scott, 2013, p8)

Although Daudt, Van Mossel and Scott (2013) acknowledged the earlier definition of scoping reviews by Arksey and O'Malley (2005) this definition removed the suggestion of the earlier definition's assertion, that scoping was a 'rapid' process. This change along with the emphasis on scoping being a literature review also drew praise from subsequent authors concerning the methodology (Pham et al., 2014)

The scoping review has become a more commonly used methodology for those conducting literature reviews. In a scoping review of scoping reviews published between 1999 and October 2012 it was noted that 68.9% of studies were completed after 2009. The same review also stated that 74.1% of all the reviews concerned health related topics (Pham et al., 2014). It is perhaps unsurprising that health related topics dominate the use of scoping reviews when considering the diversity of this field. The applicability of scoping reviews in both established and emerging fields has resulted in a greater acceptance of the methodology (Colquhoun et al., 2014).

Protocols for scoping reviews have also been published in their own right (Jolley et al., 2017; Kastner et al., 2012). These protocols have, as per this scoping review, returned to the original methodology described by Arksey and O'Malley (2005) but due to the nature of the methodology can only provide an understanding of how that particular review is conducted rather than being seen as a basis for further reviews on different topics. It is for this reason that the procedures, process and limitations of any scoping review should be reported (Pham et al., 2014) as a mechanism to inform subsequent reviews and to further address accusations of negligible rigour in comparison to other literature review methodologies.

3.2 Scoping review framework

The six stages identified by Arksey and O'Malley (2005) and enhanced by Levac, Colquhoun and O'Brien (2010) were followed to complete the scoping review. These basic scoping review models were then developed to identify occurrences of positions identified in academic literature. The six stages of the review are:

1. Identifying the research question.
2. Identifying relevant studies.
3. Study selection.
4. Charting the data.
5. Collating, summarising and reporting the results.
6. Consultation

Identifying the research question

To capture the amount of data sufficient to justify a scoping review the research question itself should be broad (Arksey & O'Malley, 2005). From the review of the framework, when identifying the question, there was also a need to consider

- A defined concept
- The target population
- The health outcomes of interest.

The rationale of the scoping review should also be established as well as an assurance that the research question will serve the purpose of the study overall (Levac et al., 2010). The rationale to understand the occurrence of positions in the literature supported the modified approach to the scoping review, as this was absolutely necessary if it was serve the purpose of the thesis.

A defined concept

The need for a modified scoping review was based around the research aims of the thesis concerning positioning theory.

1. The positioning by others
   The scoping review addresses how people living with dementia are verbally positioned in the existing literature. This clarifies whether the aim of the thesis to understand if an AI cycle with people living with dementia can influence the verbal positioning of other groups in society is socially valid.

2. The positioning by people living with dementia (the desired position)
   The scoping review needed to ascertain whether the aim of the thesis for people living with dementia to define a lived experience of ideal verbal positioning by others, had previously been addressed and whether the positioning by people living with dementia differs from other society members.

The target populations

Four individuals or groups in society act as the target populations for this thesis and are all included in this modified scoping review. Establishing target populations allowed the scoping review to be automatically broken down into sub-sets of information with verbal positioning immediately allocated to these groups from the literature rather than being collected as one large mass. When mapping the scoping review question the addition of sub-questions provides a more specific scope of enquiry beyond the broad overall research question (Armstrong, Hall, Doyle, & Waters, 2011).

The four groups included in this scoping review are:

- People living with dementia
- Family members/carers
- Healthcare workers
- Lay people

These four groups are defined as follows:

- People living with dementia

For the purpose of the scoping review a person living with dementia is identified as any person or persons within the existing literature with a diagnosis of any sub-type of dementia. In the event that the sub-type of dementia is relevant to the identified literature's outcomes or the verbal positioning in the literature is directly related to the sub-type by the authors, no distinction was made by the scoping review itself. No limitations were placed on the people living with dementia included in the scoping review in regards to any other demographics. If demographical data, such as age or gender, was highlighted by the literature's author as an influencing cause of the verbal position recorded this was included in the scoping review. Otherwise, this data was not routinely collected. The decision to discount these demographics was based on the assumption that not all pieces of the literature identified will include this information which could result in unreliable overall findings.

- Family members/carers

Verbal positioning for this group was identified as people who have a familial or social connection to the people living with dementia they are positioning. Verbal positions were accepted for members of this group when there is clear identification that the positioner has a familial or social connection to a person living with dementia involved in the same research even if the verbal position itself is related to another person living with dementia or people living with dementia. The demographical details of this group are comparable to the people living with dementia group. In this group the relationship of the positioner to the person living with dementia was collected as part of the scoping review, if this is stated, as a mechanism to inform the narrative discourse that arrived from the review. Therefore, as with other demographics, this information was not used quantitatively to assess overall positioning by the sub-members of this group due to the risk of bias.

- Healthcare workers

This group is defined as any person or persons who have a professional care giving relationship with people living with dementia. Although further insight could be achieved regarding how individual groups within the healthcare field verbally position people living with dementia (e.g. nurses, doctors, nursing assistants) the creation of these sub-groups within the sub-sets would have the same potential for bias that exists in the demographic data of the other groups. Placing all healthcare workers in one sub-set also acknowledges that the verbal positions created by this group are the experience of the people living with dementia when receiving healthcare or when being spoken about by healthcare workers, whilst separating the professional groups could result in a collection of individual positions that lack the potential for synthesis. This target population was originally classified as a nurse only group but, again, due to the scoping review outcomes being reliant on the existing literature specifying that each position was by a certain member of the healthcare worker group this was an unworkable methodology as many examples of verbal positioning would be dismissed if the designation of the positioner was not clarified.

- Lay people

Within the scoping review a lay person is identified as any positioner with no familial, social or healthcare attachment to people living with dementia who verbally positions a person living with dementia. In this definition a lay person may constitute someone who provides a service to that person living with dementia (e.g. a shop worker) but does not meet the requirements to feature in the other three target population areas. As the data was sourced from existing literature, which may provide limited data regarding the positioner, it is not possible to state whether the lay person included has a relationship (as described in the other target population definitions) with a person living with dementia. With consideration to the prevalence of dementia it is accepted that there is a high probability that many lay people’s verbal positions in the literature will be made by people who do have a familial or social relationship with a person living with dementia. However, unless this is clarified by the literature and that the verbal position relates to that person living with dementia, these entries will feature in the lay people sub-set. The scoping review will record the role of the lay person if this is stated in the literature (e.g. if the verbal position has been captured outside of controlled research).

The health outcomes of interest

The specific area of interest is the verbal positioning of people living with dementia. The four target populations identified acted as an assurance that all identified verbal positions in the literature were included in the scoping review. The inclusion and exclusion criteria for the scoping review should be clear within the research question for the scoping review (Cacchione, 2016). The research question cannot ask that the scoping review includes all verbal discourse, which could be potentially analysed using positioning theory, contained within the literature as this would involve any piece of literature that contains verbal utterances about people living with dementia. This method of inquiry would neither be practical nor provide the scoping review with the information regarding how the literature currently reports verbal positioning of people living with dementia. It is therefore not in the scope of this review to take all verbal narratives in the literature and assign positions for them. The area of interest concerns what is already known from the literature regarding verbal positioning of people living with dementia and this is integral to the research question. Scoping review methodologies have not always provided the information that the reviewers were after (Daudt, Van Mossel, & Scott, 2013) and as important as the exclusion of all verbal narratives is to limit the scope of inquiry there should also be no statements in the research question that would unduly exclude relevant literature. Literature that assigns verbal positions, but does not explicitly relate these to positioning theory, must still be regarded as valid contributions to the scoping review. The research question must remain broad whilst remaining in a distinctly pronounced scope of inquiry (Levac et al., 2010).

The research question

The scoping review research question for this inquiry was:

What is known about how people living with dementia, family members/carers, healthcare workers and lay people verbally position people living with dementia within the existing literature and how people living with dementia want to be verbally positioned?

Identifying relevant studies

A scoping review must be comprehensive (Arksey & O'Malley, 2005) in the mechanisms used to gather data. Although it has been suggested that limitations may be placed on publication dates (Armstrong et al., 2011), no limitations regarding dates were imposed. As positioning theory is a relatively new concept it did not seem necessary to limit the review in this manner. However, any literature not available in the English language at the time of the review being conducted was rejected. All results were assessed by title and rejected if deemed irrelevant to the review. Any accepted duplicate titles would then be removed prior to the screening of each abstract. Further rejections were made through this screening and all remaining literature was assessed through the full text. All accounts of original verbal positioning in the full texts were included in the scoping review results.

Data concerning the purpose and outcomes of each study included in the scoping review are included in the thesis. The focus of the scoping review, however, was the records of verbal positioning within the literature and this focus led the line of inquiry rather than a specific topic of literature. It was through the search terms, that had been derived from the literature iteratively, that relevant studies and therefore, verbal positions were found. The first search term used ('Dementia Position') was deliberately neutral to support the iterative development of further searches. All subsequent search terms were derived from search results to ensure that subsequent searches and results were based on how the literature was positioning the subject, rather than any bias from the reviewer. Whilst this meant that terms such as 'living well' were not included in the search terms, their inclusion would not have been supported by the iterative approach.

Study selection

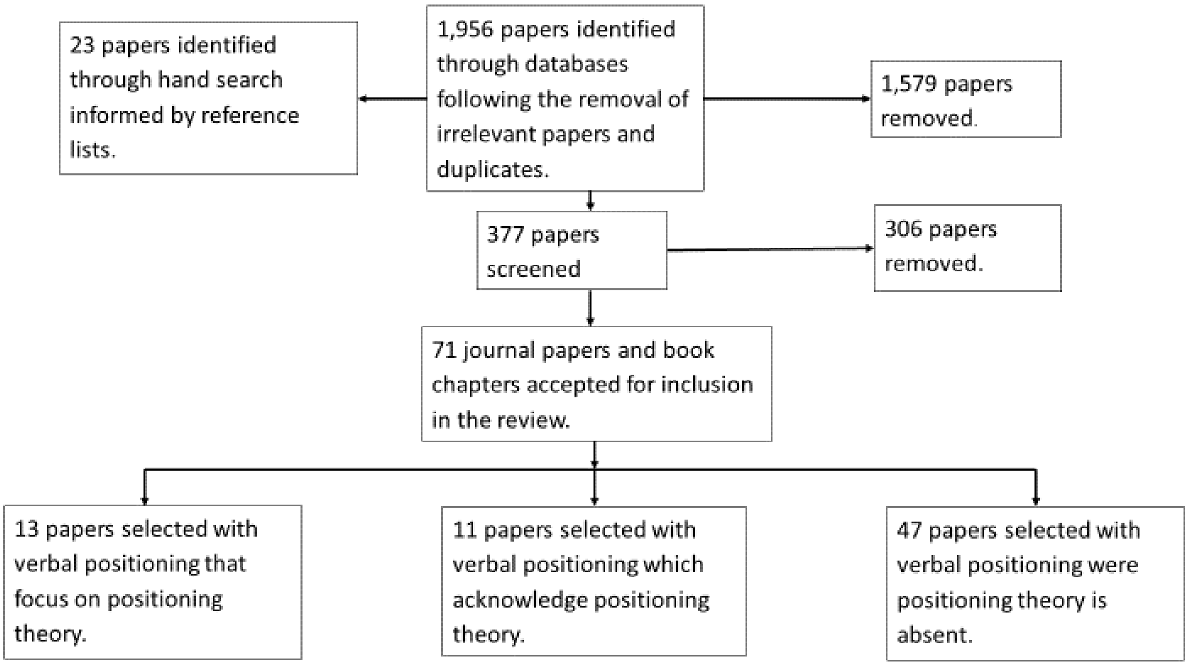
It has been suggested that a scoping review requires clearly defined inclusion and exclusion criteria for its study selection (Arksey & O'Malley, 2005). To be included, any verbal narrative had to suggest a position for the people living with dementia. When the literature did not reference positioning theory but alluded to a verbal position for a narrative in the text, these examples were also accepted into the scoping review.

The objective of the scoping review was to understand what was known about how people living with dementia are positioned in the literature. As positioning theory is a mechanism for analysis within academic literature, this was the focus of the scoping review. Whilst it would be possible to analyse any literature for positions, it was not the aim of this review to complete a positioning analysis on any discourse but to identify what was already available in the literature regarding how people living with dementia are positioned. This excluded literature including policies, newspaper reports, biographies and autobiographies from the review, which after positioning analysis would be likely to provide evidence of positioning but would require an original analysis rather than meeting the requirements of this review. Seven discrete searches were conducted for the review. The searches are detailed in Appendix 7.

Overall identification and selection of papers

Although the overall amount of papers identified resulted in limitations being placed on the scoping review, the comparative amount of papers included in the review was relatively small. This outcome certainly supported the use of a scoping review methodology as the papers could not have been identified through the stricter processes of a systematic review. The overall search and selection process is documented in Figure 12.

Figure 12: Scoping review selection flowchart



By completing this search of databases and the subsequent hand search of papers it is clear that although the verbal positioning of people living with dementia is featured in the literature there are considerable gaps in the research regarding its illustration and the theories surrounding the subject.

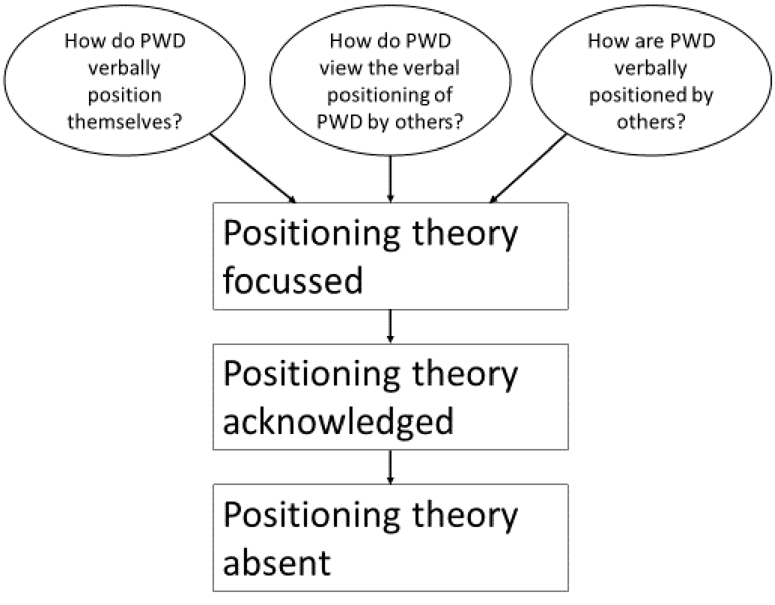
Charting the data

A challenge of charting the data in scoping reviews highlighted by Levac et al (2010) is that the nature and extent of data to be extracted is unclear in Arksey and O'Malley's (2005) original guidance. To answer the review question it was necessary to collect all accounts of verbal positions in the identified literature.

Overall literature results charts

The overall contributions of each paper have been divided into three themes (related directly to the research question) which each contain three sub-themes (recognising the inclusion or absence of positioning theory), as illustrated in Figure 13. The process of thematically representing the data was recommended by Arksey and O'Malley (2005) with further recommendations later added regarding the identification of sub-themes (Daudt et al., 2013). The application of this theming supported the modified approach to the scoping review as the direct application of positioning theory was not always clarified in all the included literature.

Figure 13: Contributions of literature and the inclusion of positioning theory

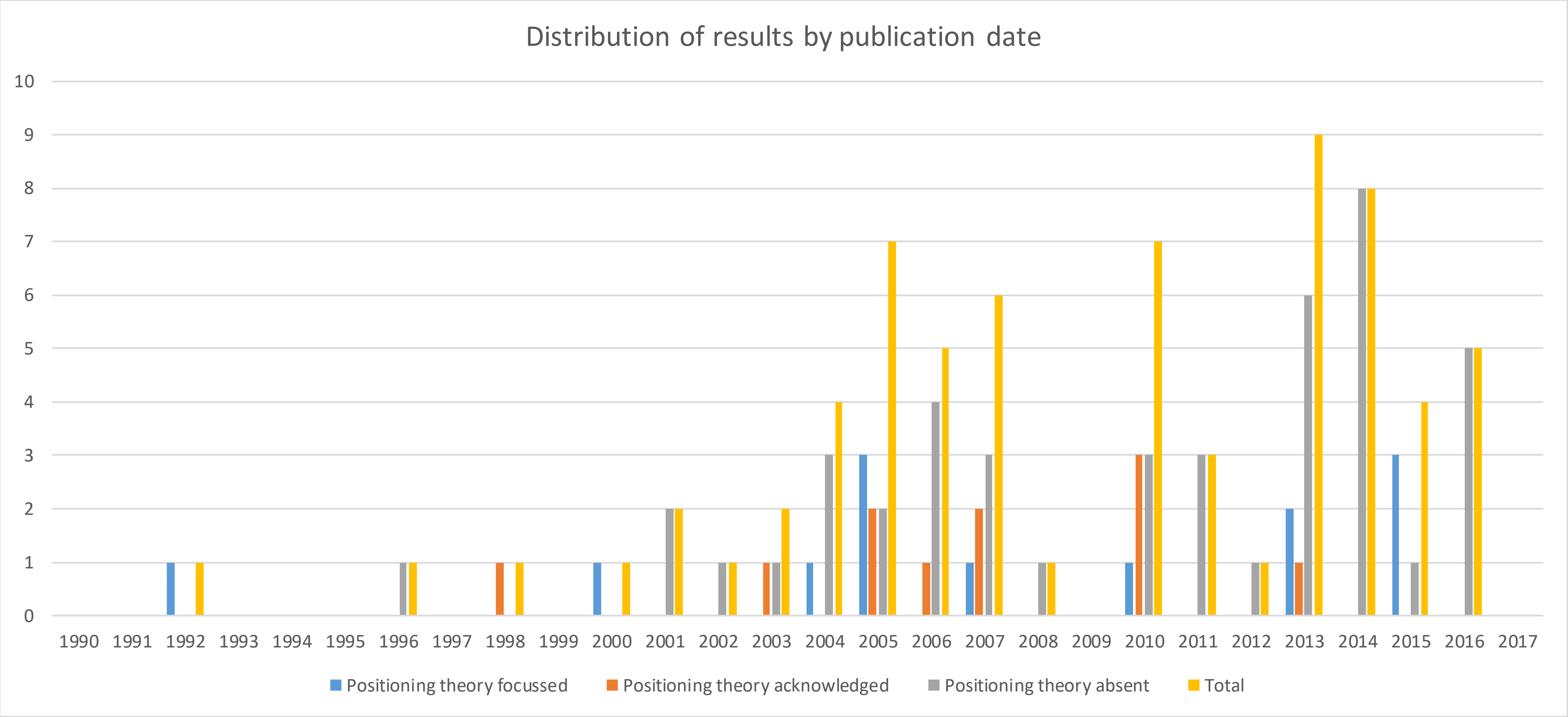


Quality Appraisal

The guidance on conducting scoping reviews from the Joanna Briggs Institute is based on the frameworks of Arksey & O'Malley (2005) and Levac et al (2010). The institute describes scoping reviews as an overview of a subject, regardless of the quality of studies included and that they do not exist to appraise the quality of evidence (Peters et al, 2020). A quality assessment phase has been recommended by some reviewers (Daudt et al., 2013; Levac et al., 2010) with criticism that guidance advising against quality appraisal may tempt reviewers to ignore the quality of studies to expedite their outcomes (Munn et al, 2018). Other reviewers have stated that an assessment of quality is not required and should only be included if there is a specific requirement for its inclusion (Peters et al., 2015; Peterson, Pearce, Ferguson, & Langford, 2017, Sucharew & Macaluso, 2019). The majority of published scoping reviews do not include a critical appraisal and whilst some of these studies use formal tools to assess quality, others are more subjective (Pham et al, 2014). Scoping reviews have been described as 'wide (although maybe not deep)' (Dijkers, 2015 p2) and although this could reflect the lack of quality assessment that generally persists in scoping reviews there should also be an acknowledgement of the sheer breadth of data inclusion that can be typical of this methodology. The conclusions of scoping reviews should align to the review question (Peters et al, 2015) and for this review, the conclusion of how people living with dementia are positioned in literature would be unaffected by a quality appraisal. Scoping reviews look to describe what is known rather than analyse study quality (Lockwood, dos Santos & Pap, 2019) and whilst quality appraisal has been recommended for scoping reviews, which aim to influence clinical practice (Munn et al, 2014), there is not an expectation that this appraisal should be commonplace. The consensus of a large body of scoping review academics (Tricco et al, 2018) is that the purpose of scoping reviews is not to appraise quality and reviewers who do include a quality appraisal should provide a rationale for doing this whilst reviewers should not have to provide a rationale for not including a quality appraisal. In the context of this scoping review the research question is dependent on the accuracy of reported verbal positions rather than the quality of the overall paper. For the purpose of this review, a quality assessment would not have enhanced the review's ability to answer the review question.

The papers selected for inclusion are presented in Appendix 8. Figure 14 illustrates the papers accepted by year of publication.

Figure 14: Included papers illustrated by year of publication



Collating, summarising and reporting the results

Every verbal position identified in the literature (755 results) was analysed using positioning theory, whilst acknowledging Braun and Clarke's (2006) framework for thematic analysis to report overarching domains, themes and sub-themes. The dimensions of self and other positioning, as suggested by Davies and Harré (1999), influenced the initial coding of themes. These dimensions include the proposition that no positions belong in a non-contradictory linear biography but instead represent fragments of a living life story. When coding the verbal positions from the literature it was not possible to place the positions within the lived biography as verbal positions often existed in isolation with no further demographical data beyond a dementia related diagnosis. This limitation did not prevent the application of codes due to the research question asking how people living with dementia are verbally positioned within the context of the literature itself.

When analysing examples taken from the literature the occurrence of first order positions dominated. Although verbal positions within the context of their conversation may have represented second order positions, within the literature second order positioning could not be presumed. Incidents of second order positioning were collected (Roach, Keady, Bee, & Williams, 2014) but the dominance of first order positions was indicative of the data collection method rather than an a positive indicator that first order positioning is dominate in the conversations about people living with dementia.

Initial coding was completed whilst embracing the requirement for the analysis to be inductive. All theming was borne out of the data with no preconceived theming used to influence the practical coding. Thematic analysis has been described as generally taking either a semantic or latent approach to data (Braun & Clarke, 2006). A semantic approach was taken to the data extracts with all verbal positions acknowledged as literal positions but a latent process was incorporated as data was interpreted into themes beyond the descriptive utterances. Although coding can be completed using software programmes (Braun & Clarke, 2006), all coding was completed manually in recognition of the iterative process of scoping reviews.

During the first round of coding, the verbal positions had been placed within 73 codes. Coding was repeated before an initial thematic map was developed using the identified codes to establish thematic patterns. By assessing the codes and themes using positioning theory it was evident that the coding itself was a perlocutionary force but the five themes were more suitably placed within the confines of illocution (what was achieved *in* the positioner's utterance). Each verbal position had an illocutionary mechanism that placed it within the context of a theme whilst the perlocutionary force reflected the actual effect of the utterance which was evident in the codes.

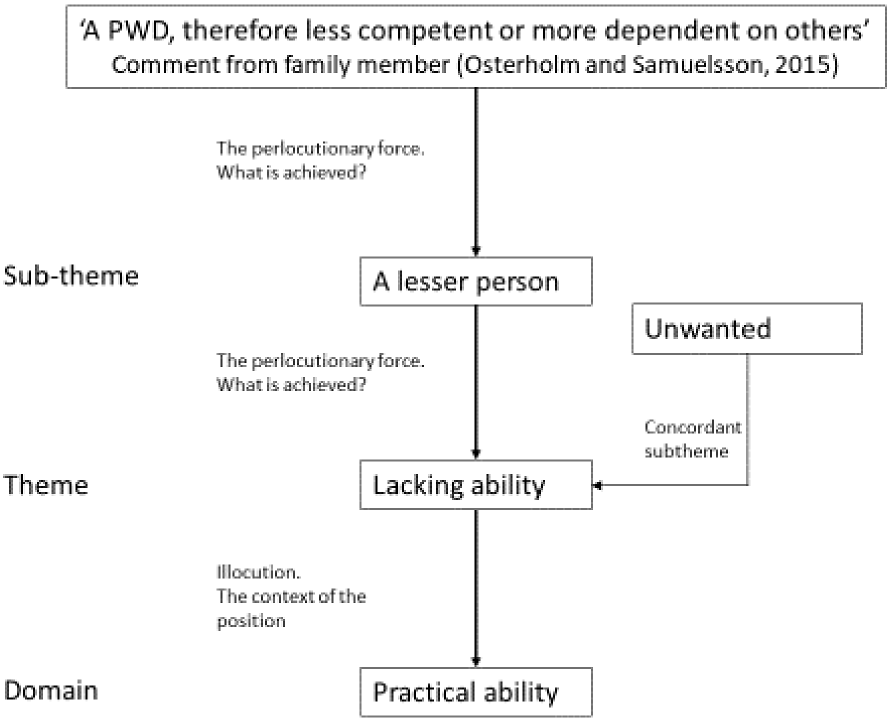
Following the creation of the thematic map, the framework for analysis was continued through the reviewing of themes (Braun & Clarke, 2006). Through a process of refinement it became evident that several codes could be merged without losing the clarity of the perlocutionary force. The five themes were further refined but there was an evident thematic gap between the codes and themes. A cycle of secondary theming created a new set of themes that acknowledged a perlocutionary theme that the perlocutionary codes could be attributed to. Codes and themes were continually refined until results remained consistent during subsequent analysis.

The analysis created three sets of data.

1. Perlocutionary statements that had arisen from coding that were developed into 38 **sub-themes**.
2. 16 perlocutionary **themes** that created an overall meaning to the statements.
3. Five **domains** that acted as an illocutionary mechanism to identify the subjects in which people living with dementia are positioned.

Each verbal position was assigned to all three sets of data, as illustrated in the example (Figure 15).

Figure 15: Example of verbal position allocation to domain, theme and sub-theme.



3.3 Domains, themes and sub-themes

The three data sets were created through the analysis. The definitions of each data set continually evolved through each iteration of coding and theming. The final data set descriptions are illustrated here:

Domain: Societal standing

These entries are related to how the person living with dementia is positioned in the context of society. The four themes either recognise people living with dementia as having a continued presence within society, excluded from society, having reduced rights in comparison to their previous standing or others in society and as removed from society.

Theme: Part of society

The person living with dementia is positioned as a continuing member of society in some capacity. The sub-themes acknowledge that the positions may be personal or within larger society.

Sub-theme: Family

Positioned as being a family member or through language that suggests the relationship between family members.

Sub-theme: Friendship

Positioned as belonging in a friendship. The position is not provided by a family member and indicates that the positioner (when not the person living with dementia) has a non-healthcare based relationship with the person living with dementia.

Sub-theme: Wider

Positions that include the person living with dementia as being part of wider society (i.e. not within the confines of just family and friendship).

Theme: Excluded

The person living with dementia is positioned as removed from other people. The sub-themes illustrate the direct positioning of the person living with dementia as excluded and how the language or actions of others have upheld this exclusion.

Sub-theme: Alone

The person living with dementia is positioned as being physically or psychologically isolated.

Sub-theme: A victim of others

Positions that allude to the role that other people in society may have in the physical and psychological isolation of the person living with dementia.

Theme: Reduced rights/roles

The person living with dementia is positioned with less worth than other people in society whether that is due to the diagnosis, the consequence of their symptoms or a standing that the person living with dementia does not require the same consideration as before.

Sub-theme: Not worthy of thought

Harm to the person living with dementia is positioned as being less important in comparison to others and the person living with dementia is not acknowledged in conversations about themselves or their care.

Sub-theme: Worthy of derision

Positioned by incidents that have occurred following diagnosis that others view with contempt and therefore the person living with dementia can be treated with contempt.

Sub-theme: A patient, not a person

Positions that label the person as a patient or in relation to dementia

Sub-theme: Diseased

The person living with dementia is positioned within the context of a disease and suffering with positioning of the person themselves absent.

Theme: Lost humanity

The person living with dementia is positioned as different to other people or unrecognisable to the positioner's concept of humanity.

Sub-theme: Less than a person

Positions suggest someone or something that is either no longer human or should be unable to access the same rights and resources as before.

Sub-theme: Not like us

Positions that separate the person living with dementia from the rest of society (personally or in the context of wider society). The position of person living with dementia as 'other'.

Domain: Practical ability

These entries are related to how the person living with dementia is positioned regarding their ability to practically achieve their goals. The three themes are concerned with a lack of skills and therefore the person living with dementia is positioned as requiring help, a lack of skills that positions the person living with dementia as less than they should be and positions that reflect continuing practical abilities.

Theme: Dependent

The person living with dementia is positioned as lacking the skills to manage their daily life and therefore requires occasional or continuous assistance from others.

Sub-theme: No longer capable

Positions the person living with dementia as being unable to complete tasks that would have previously been achievable.

Sub-theme: Need help from others

Positioned as requiring practical verbal or physical support from others.

Theme: Lacking ability

The person living with dementia is positioned as not achieving what they should be or being less than they should be. This also contributes to the person living with dementia being positioned as an undesirable presence or burden.

Sub-theme: A lesser person

Due to the deterioration in ability the person living with dementia is labelled as less than what the positioner expects them to be. The person living with dementia is below the expectations of others.

Sub-theme: Unwanted

The person living with dementia is positioned as having no beneficial qualities regarding their abilities and is an unhelpful and unnecessary disruption to others.

Theme: Current ability

The person living with dementia is positioned by an acknowledgement of what they are still able to practically achieve with a recognition that some things may have improved.

Sub-theme: Better than I was

Positioned as having positive changes since the diagnosis of dementia.

Sub-theme: An able person

The continuing abilities of the person living with dementia are used to position them as remaining practically useful to their own lives and others.

Domain: Internal values

These entries are related to how the person living with dementia is positioned regarding their inner traits and beliefs, and how these are interpreted by the positioner. The two themes examine these traits as they are viewed by the positioner with either a negative or positive lens.

Theme: Negative core

The person living with dementia is positioned as changed in their ethics, morals, behaviour or standards in a manner that is unfavourable to the positioner.

Sub-theme: A person lacking quality

Changes in the person living with dementia’s personality are used to create positions of either pitiful helplessness or selfishness.

Sub-theme: A problem

Positions that suggest a malicious intent to the person living with dementia’s actions or the person living with dementia as an obstacle in the lives of others.

Theme: Positive core

The person living with dementia is positioned as unchanged or improved in their ethics, morals, behaviour or standards in a manner that is favourable to the positioner.

Sub-theme: A person of quality

The person living with dementia is positioned in respect to their continuing or improved personality traits and beliefs.

Sub-theme: Resilient

Positioned as having great strength in response to their diagnosis.

Domain: An evolving self

These entries are related to how the person living with dementia is positioned regarding their personhood. The four themes are related to continued personhood, altered self, shattered personhood and the person living with dementia as undesirable.

Theme: Disintegrating self

The person living with dementia is positioned as either lacking or losing their personhood.

Sub-theme: Finished

The person living with dementia is positioned as unrecognisable to the person they used to be.

Sub-theme: Disappearing

Positioned as no longer fully present regarding their individual personhood.

Theme: Unwanted self

The person living with dementia is positioned as having a malignant personhood.

Sub-theme: Unpleasant

The person living with dementia is positioned as having characteristics, possibly malicious, which the positioner views as repugnant.

Sub-theme: Don’t go near

Positioned as someone or something that is likely to cause harm or annoyance to another person

Theme: Changing self

The person living with dementia is positioned as individually greater than the diagnosis but individually altered from the person they were before.

Sub-theme: A different person

The person living with dementia is positioned as having personhood but not the same as before.

Sub-theme: More than a diagnosis

Positions the person living with dementia as not just being a reflection of dementia. A person still remains.

Theme: Maintaining self

The person living with dementia is positioned as unchanged regarding their own sense of self and how they present to others. They may be regarded as the same as others and with a continued sense of their own identity and personhood.

Sub-theme: Normal

Positioned as unremarkable but the same as other people without dementia. Positions may include a role.

Sub-theme: The same person

Positioned with an ongoing sense of continued individual personhood.

Sub-theme: Not like other person living with dementia

Positioned in comparison to the positioner's view of other person living with dementia regarding the person living with dementia being unlike others with dementia.

Domain: Control over life

These entries are related to how the person living with dementia is positioned regarding how they and others perceive their current capacity to make decisions and influence their own lives. The three themes examine positions that suggest the person living with dementia completely lacks capacity or control, remains in control or wishes to have control and positions that suggest the person living with dementia requires protection due to deteriorating capacity.

Theme: No control

The person living with dementia is positioned as being unable to provide any worthwhile insights into their current situation.

Sub-theme: Don’t know what’s going on

Positions that suggest the person living with dementia lacks insight and the competence to be involved in decisions.

Sub-theme: Nothing to offer

Positions that leave the person living with dementia out of conversations or decisions about themselves.

Theme: Having control

The person living with dementia is positioned as either wanting to have control over their own life or continuing to maintain control.

Sub-theme: Master of own destiny

Positioned as wanting to be involved in decisions about their own life and wanting to influence this.

Sub-theme: Know own mind

The person living with dementia is positioned as being able to let others know their opinions and what they want.

Sub-theme: Still capable

Positioned as continuing to have insight with an ability to function and grow as they make decisions.

Theme: Diminishing control

The person living with dementia is positioned as requiring help from others due to diminished capacity and positions that recognise the influence of dementia on this deteriorating control.

Sub-theme: Not well

Positions that use the symptoms or diagnosis to suggest a person living with dementia with less control than might be perceived.

Sub-theme: Losing control

Positioned through a recognition that the person living with dementia’s ability to take control is reduced and deteriorating.

Sub-theme: Need protection

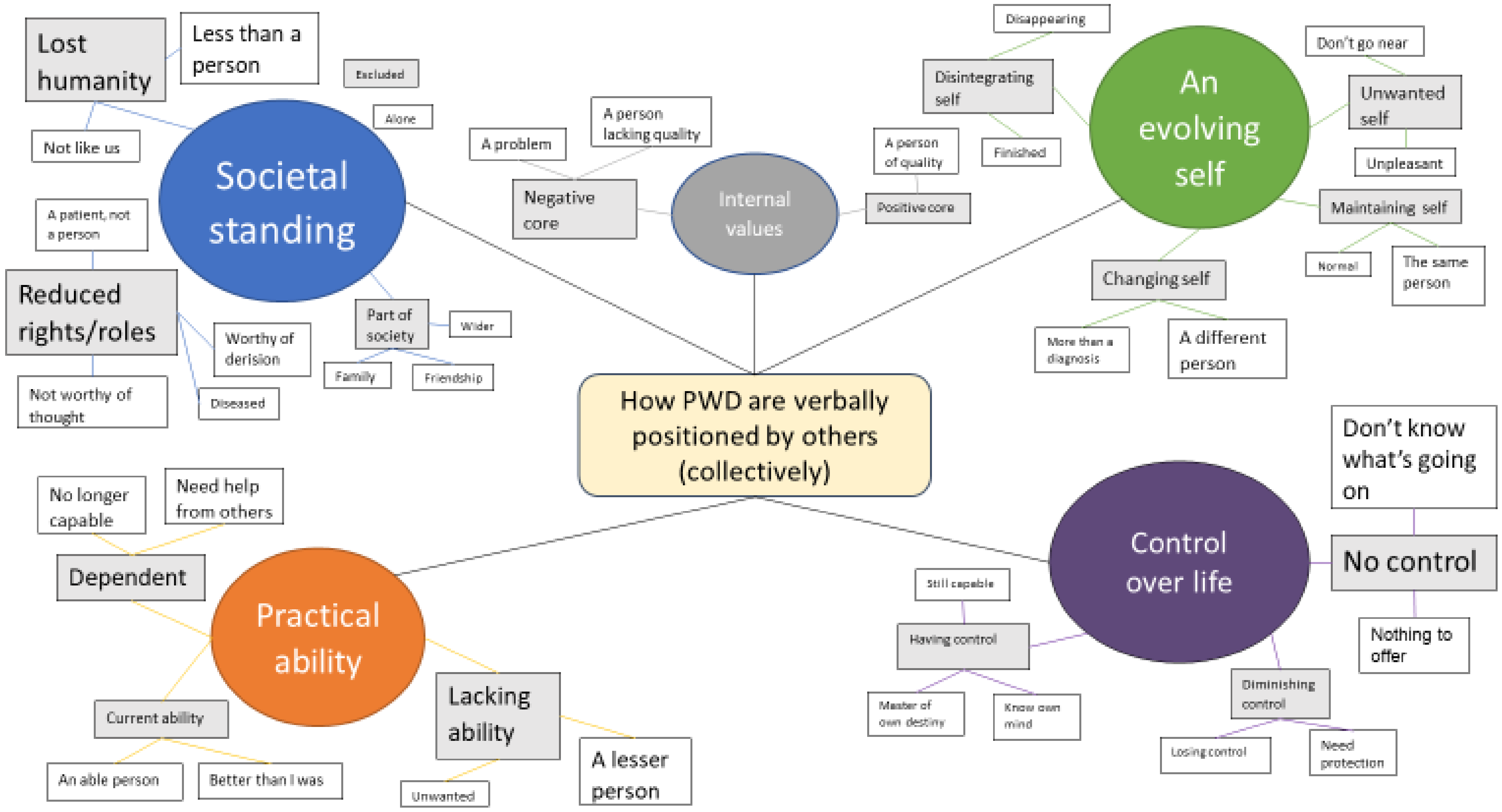
Positions that suggest the person living with dementia would be vulnerable if left to maintain their own life and decisions

Graphical representation of data

The thematic analysis reflects the diverse outcomes of a scoping review with the ability for the reviewer to act developmentally and intellectually creatively a strength of the methodology (Davis, Drey, & Gould, 2009). Although some reviewers have suggested that scoping should result in limited statistical information (Peters et al., 2015) whilst others have suggested that synthesis is minimal with graphical representation of data the primary outcome (Peterson et al., 2017), the methodology has successfully provided a mechanism for both statistical and narrative data in relation to verbal positioning.

Individual verbal positions were numerically charted and recorded within each sub-theme, theme and domain. Graphically, themes are displayed in percentiles (within the narrative) whilst an overall display illustrates the three data sets by using text size to illustrate occurrence. Included in the text is the visual representation of overall verbal positioning by others (not people living with dementia) concerning people living with dementia (see Chart 1)

Chart 1: The overall verbal positioning of people living with dementia by other groups in society



3.4 Narrative analysis of scoping review results

The narrative of the scoping review is aligned with the data sets that were created during the thematic analysis using positioning theory.

3.4.1 Societal standing

Part of society

The frequency of positioning occurrences within the literature regarding people living with dementia as *part of society* suggests that either people living with dementia believe that the acknowledgment of their societal belonging should be made more frequently or that other groups are less inclined to view people living with dementia as automatically belonging to society (see Chart 2 and 3).

Chart 2: Societal standing: How people living with dementia verbally position themselves and other people living with dementia

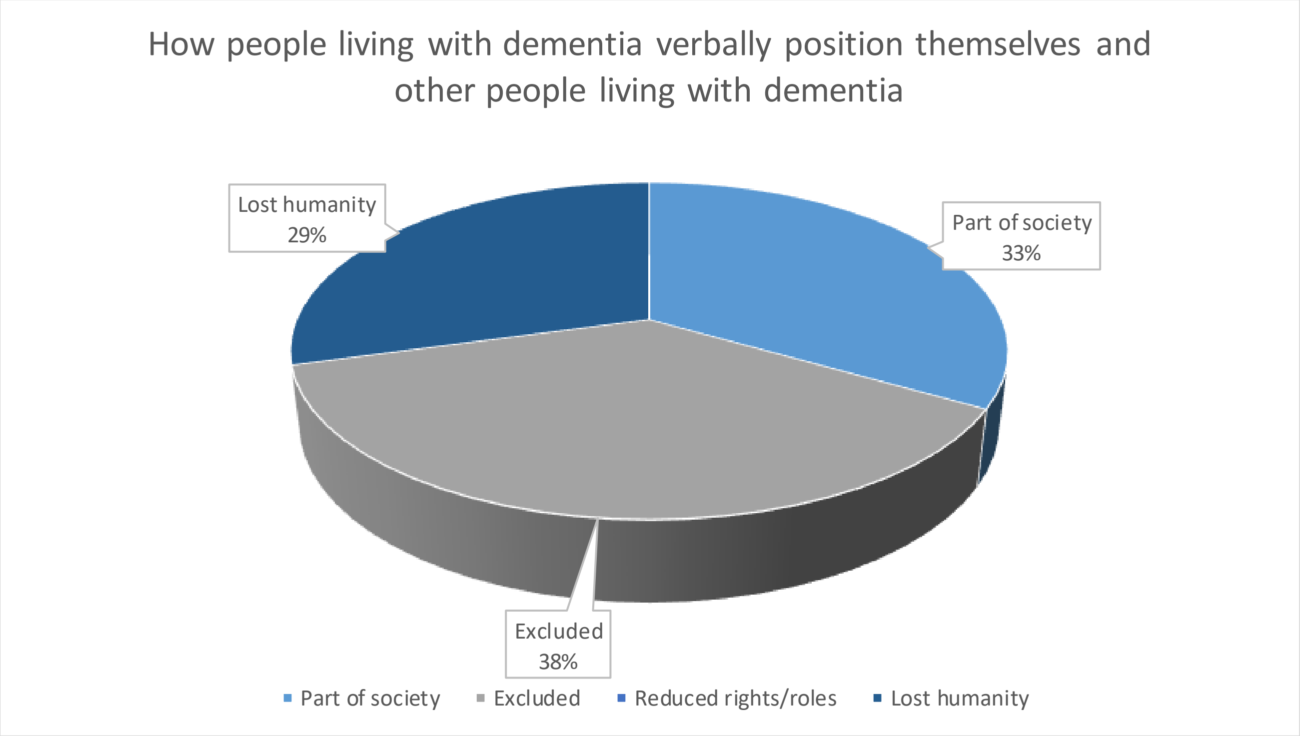
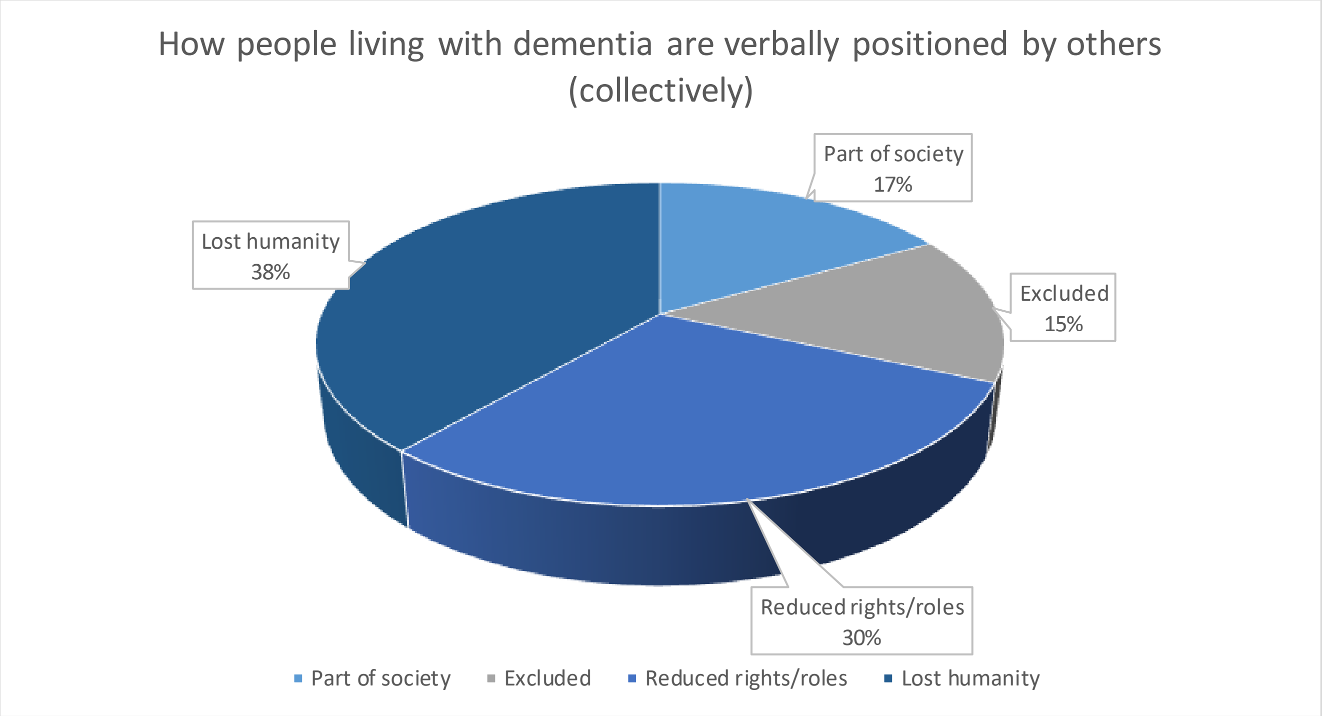


Chart 3: Societal standing: How people living with dementia are verbally positioned by others (collectively)



Being placed as part of a *family* is the most frequently occurring position within the *part of society* theme. This is most regularly observed by the pronouns ‘us’ and ‘we’ which occur more frequently in the literature when the positioner is the spouse of the person living with dementia, which suggests the maintenance of the relationship as a stable social unit (Hydén & Nilsson, 2015). A stable social relationship creates an environment, which allows the use of individualistic pronouns without fear of rejection by family member(s). However, the existence of stable social units is limited in the literature with more than a twofold occurrence in the positioning by people living with dementia regarding being *part of society* in comparison to the family group.

Friendship is the least prominent position of the three societal groups with three of the four examples taken from one piece of literature focussing on how to position oneself in relation to a loved one with dementia (Arieli, 2013). The sparsity of *friendship* positions within the literature could suggest that the concept of friendship is less regarded by people living with dementia and others. However, the lack of examples of *friendship* positioning is also convergent with prominently familial positioning in the literature.

Although being positioned as part of *wider* society is well captured in the literature, examples suggest that there are conceptual differences between positioning groups regarding what it means to be positioned as part of *wider* society. Being ‘liked’ (Surr, 2006) is included in people living with dementia’s own positioning which is valuably different from the healthcare worker's positioning of the person living with dementia as a 'citizen' (Larsen, Normann, & Hamran, 2015). Although the lay people example, 'we're all human beings' (Clarke & Bailey, 2016) creates a position of being part of *wider* society it reflects a dissonance between how each group views the person living with dementia's place in society. The people living with dementia example suggests a societal presence due to individual favourable characteristics, the healthcare worker suggests it is due to long term civilian rights whilst the lay person example is solely based on the person living with dementia's genetic existence.

Reduced rights

No entries relating to people living with dementia positioning themselves or others in regards to *reduced rights* existed within the literature. As a collective, the incidence within other groups was almost a third of all societal positioning (see Chart 3) whilst over half of the positioning by health workers within the theme of societal standing related to *reduced rights* (see Chart 4). The absence in the positioning by people living with dementia does not reflect an ignorance of the *reduced rights* subtheme within the people living with dementia group as several examples are included in the views of how people living with dementia feel they are positioned by others (see Chart 5).

Chart 4: Societal standing: How people living with dementia are verbally positioned by healthcare workers

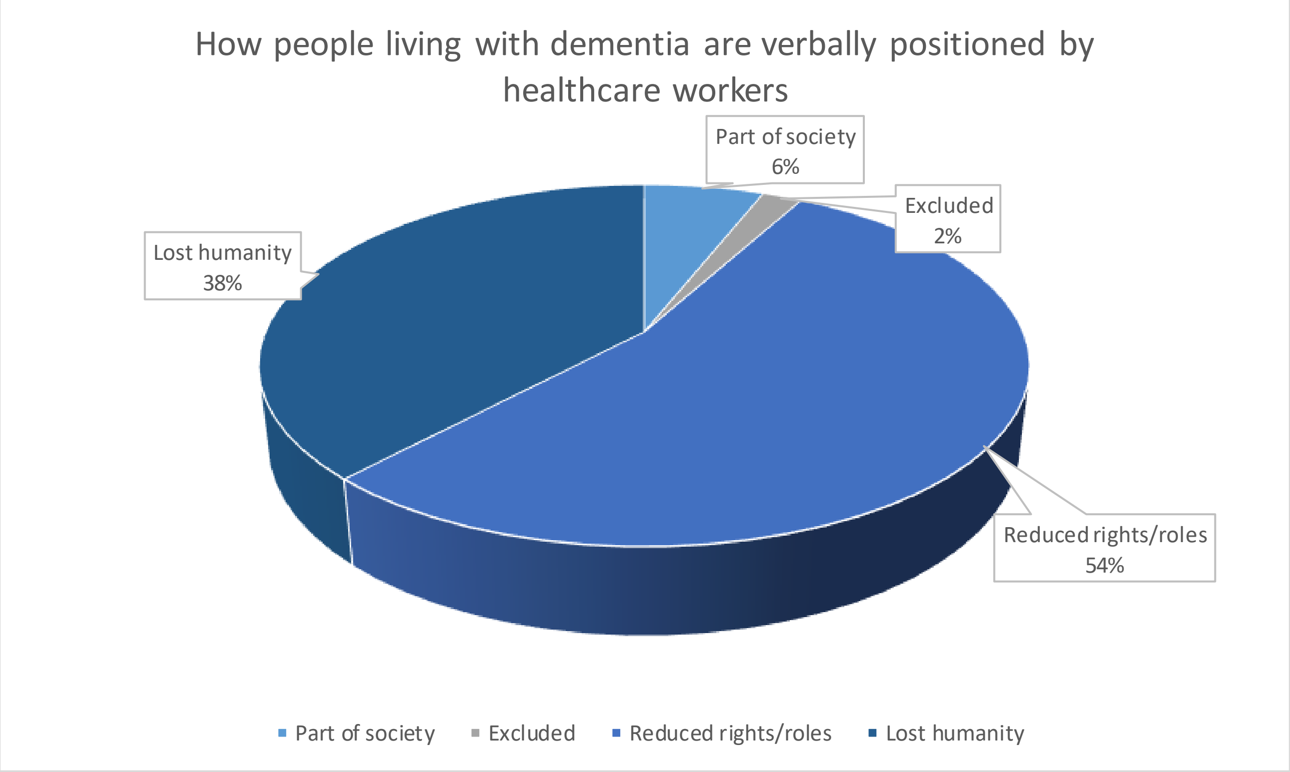
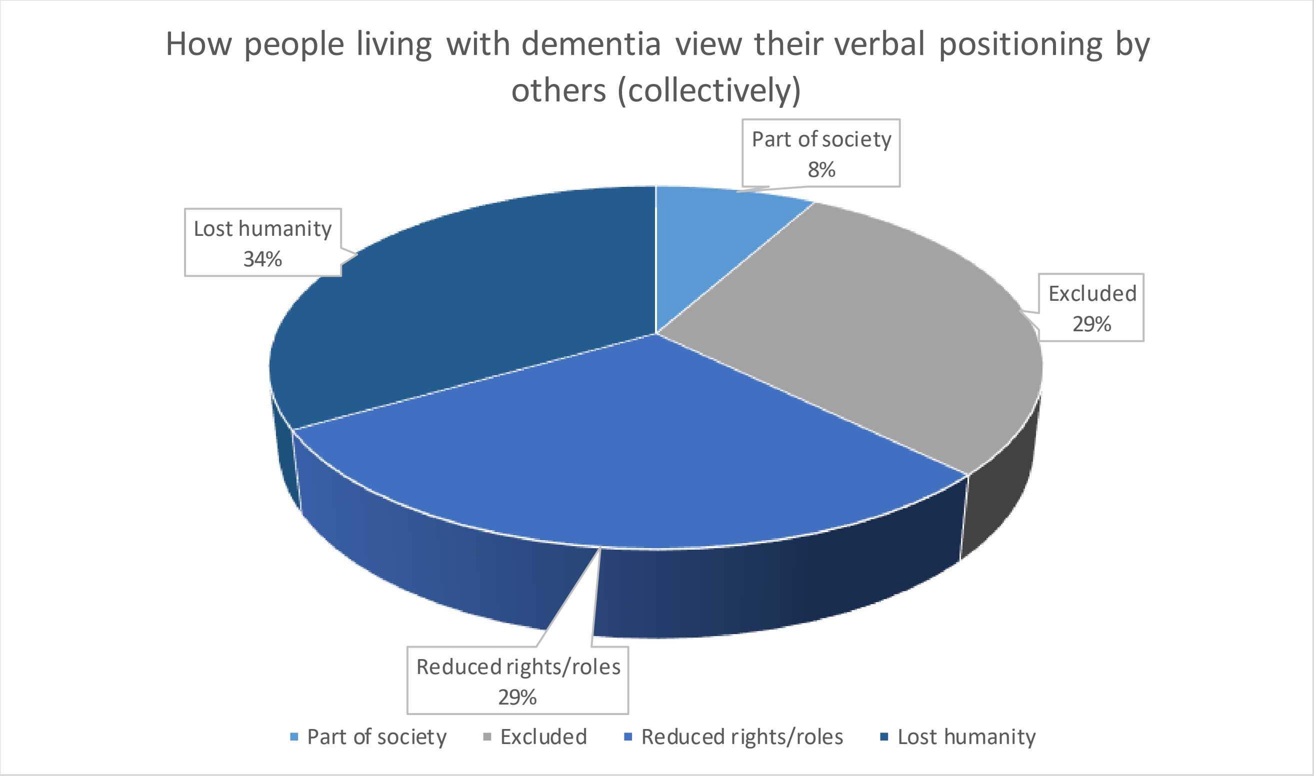


Chart 5: Societal standing: How people living with dementia view their verbal positioning by others (collectively)



Entries in both family and health worker domains tied the concept of the person being *not worthy of thought* with the belief that negative experiences have minimal effect on the individual. Verbal abuse is suggested when the family member discussing an argument states 'it doesn't have much of an impact' (O'Shaughnessy, Lee, & Lintern, 2010), suggesting that what is said to the person will have no ill effect and there is no requirement to consider the person during conversation. Physical abuse is implied when being raped is described as 'no lasting harm' as the person won't remember it (Sabat, 2006). This positioning implies that the subject has limited or no worth and lacks the civil rights of other human beings who have the same experience. By positioning the person as *not worthy of thought* they are powerless to personally react or gain support following negative experiences.

Statistically the occurrence of positions regarding the person living with dementia as *a patient, not a person* and as *diseased* are identical in the literature concerning family and health workers. Two examples of *diseased* positioning by family members are observed in the person living with dementia being described as 'contagious' (Liu et al., 2008; O'Shaughnessy, Lee & Lintern, 2010), which suggests the potential for others to become infected by the person and have their own position degraded. The health worker example reporting the person shouting as 'it's the dementia' (Bourbonnais & Ducharme, 2013) aligns with previous examples that negative experiences have a limited impact. This suggests that if people living with dementia attempt to communicate their need or reposition themselves it will be viewed as a symptom of dementia, thus denying them their expressive right.

Excluded

Other groups positioning of people living with dementia in the literature as *excluded* occurs relatively infrequently in comparison to people living with dementia's own positioning and how people living with dementia view their positioning by others (see Chart 2 and 5). There are no records in the literature of other groups positioning people living with dementia as *a victim of others*, perhaps not recognising the sense of isolation or estrangement noted by people living with dementia. The example by family, 'I think people like that live in a little world of their own' (Walters, Oyebode, & Riley, 2010) suggests that the positioning of the person as *alone* is a result of their behaviour following the onset of dementia. People living with dementia allocate the position of *alone* through presentations of isolation and the fear of making 'a fool of myself' (Caddell & Clare, 2011).

Although the position of being *a victim of others* is only observed in the examples by people living with dementia and their view of others positioning there are differences in the meaning behind some of these positional examples. Examples including terms such as ostracised, stigmatised and betrayed suggest that the person is a victim of others but do not suggest any attempted secondary positioning by people living with dementia. Other examples include the person 'fighting to be heard' (Shakespeare & Clare, 2005) and wanting to argue regarding their negative positioning by others (Preston, Marshall, & Bucks, 2007). These latter examples suggest a denial of an attempt at repositioning. An inability to reposition oneself as not a victim is exacerbated further when 'people tend to talk…behind your back' (Harman & Clare, 2006).

Lost humanity

The position of *lost humanity* occurs more frequently in all groups in comparison to how people living with dementia position themselves and other people living with dementia (see Chart 2 and 3). Examples of people living with dementia creating the position of being *less than a person* are predominantly through language that is suggestive of decreasing worth, the person being no longer of use and even fit for the rubbish bin (Langdon, Eagle & Warner, 2007). Other examples suggest a psychological and possibly a physical metamorphosis with graphic illustrations of 'the living dead' (MacRae, 2010). People living with dementia's acknowledgement that they no longer feel like a person (Van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2014) is unclearly contributed to the physiological changes caused by dementia or other's positioning within the theme of *lost humanity*.

Positioning of the person as *less than a person* is somewhat different in other groups. In familial positioning, humanity appears to still be acknowledged in some examples with the person living with dementia described as depersonalised, suggesting a lack of personhood but within a physically human frame. Other examples create or acknowledge an objectification and suggest that humanity is lacking and the person is little more than a lump of matter. The person as 'alien' (Robertson, 2015), creates a similar position to the person living with dementia's own 'living dead' (MacRae, 2010). Examples that depersonalise, objectify and identify the individual as something other than a person collectively inform other familial examples of the person living with dementia as being no longer necessary (Clare, 2003).

The person living with dementia as *less than a person* is illustrated in the health worker example that 'treating an Alzheimer's patient is like doing veterinary medicine' (Sabat, 2003). This can then be tied to the subtheme of *reduced rights* as within this position the legislation of human rights would not be applicable.

The person living with dementia is positioned as different to other people in society in examples that suggest the person is *not like us*. When the person was positioned by family members as *part of society* within the *family* subtheme this was often through the use of the pronoun 'us'. A *not like us* position is created by the pronoun, 'them'. The use of 'them' is not exclusively negative within the context of use but creates the position for the person as different. Health workers describe people living with dementia as not the same as 'us' (Arieli, 2013). The adjective pronoun 'others' is used by lay people (Townsend, Godfrey, & Denby, 2006). The positioning of people living with dementia as *not like us* suggests they lack personhood and in some examples, lack humanity.

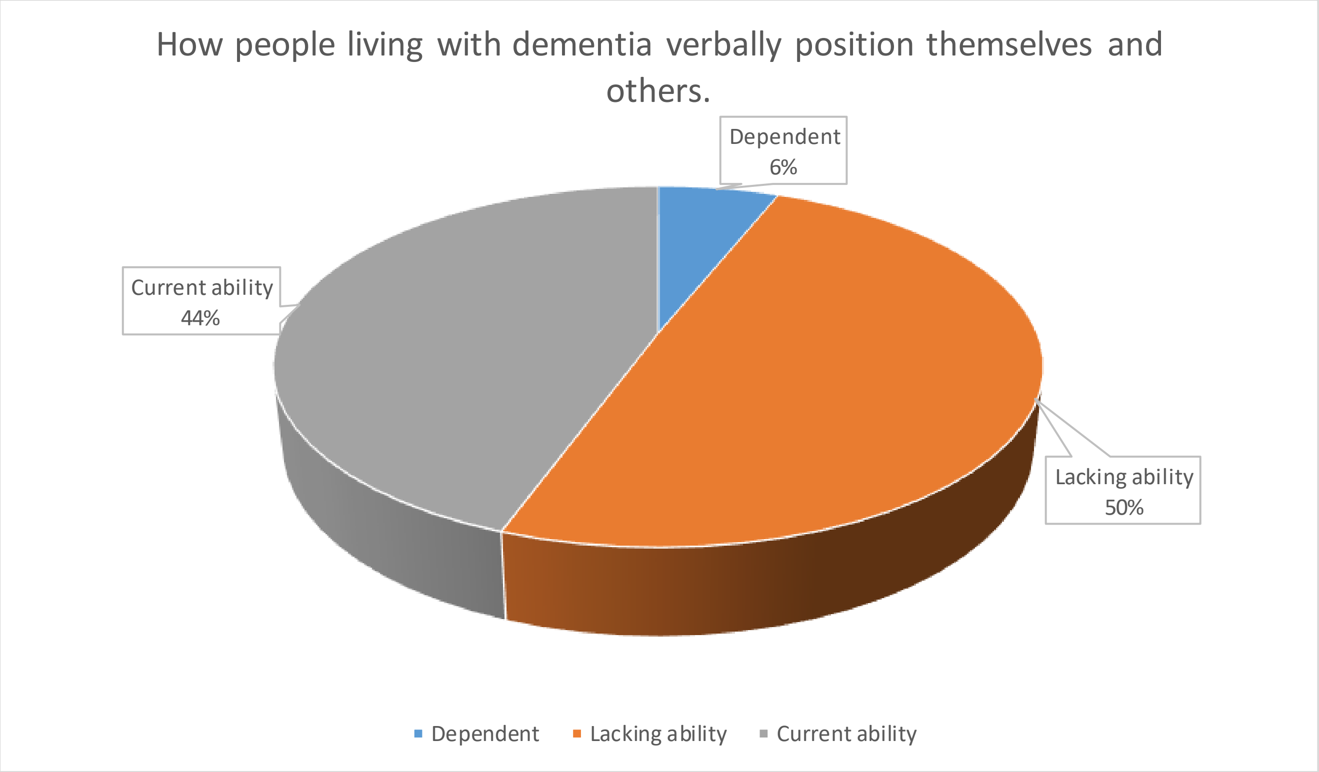
3.4.2 Practical ability

Dependent

As the deterioration in functional abilities is an expected outcome of dementia the positions within the *dependent* sub-theme, *no longer capable* and *need help from others* should not be an assumed pretext of negative positioning by others. A consequence of requiring practical assistance is that the *dependent* position is allocated more frequently by other groups in comparison to people living with dementia as helpers position themselves as a solution to a functional deficit.

The occurrence of *dependent* positioning by people living with dementia is limited (see Chart 6) although the example of 'useless' (Offord et al, 2006) in the *no longer capable* sub-theme displays that the acknowledgement of declining abilities is made by people living with dementia speaking to other people living with dementia when there is no person holding a helper role present. The person living with dementia's view of others who 'question her ability' (Hedman et al, 2012) suggests that positioning by others does not always reflect their belief in their abilities. This example was supported within the text as people living with dementia acknowledged the importance of others in the maintenance of their selfhood but recognised a reduction in support as the symptoms of dementia worsened.

Chart 6: Practical ability: How people living with dementia verbally position themselves and others



The presence of malignant positioning versus factual commentary can be difficult to ascertain within the examples of familial positioning. The example, 'unable to use money' (Roach et al, 2014) is a spouse's observations of a task that the person living with dementia is unable to complete. The same spouse provides the example 'unable to socialise', an activity less defined than using money and when placed in context of a person who is still driving and setting the household alarm it appears to create an unduly negative position for the person living with dementia.

The dominance of others positioning people living with dementia as *dependent* (see Chart 7) is continued within the *need help from others* subtheme. As with other positions within the *dependent* theme this may be a reflection of what the positioner is doing to practically assist the person rather than be a reflection of negativity towards them. The high occurrence of ‘dependent’ examples within healthcare worker positioning (see Chart 8) may be a practical outcome as this group tends to have contact with people when they require healthcare assistance and therefore the position is the basis for their relationship.

Chart 7: Practical ability: How people living with dementia are verbally positioned by others (collectively)

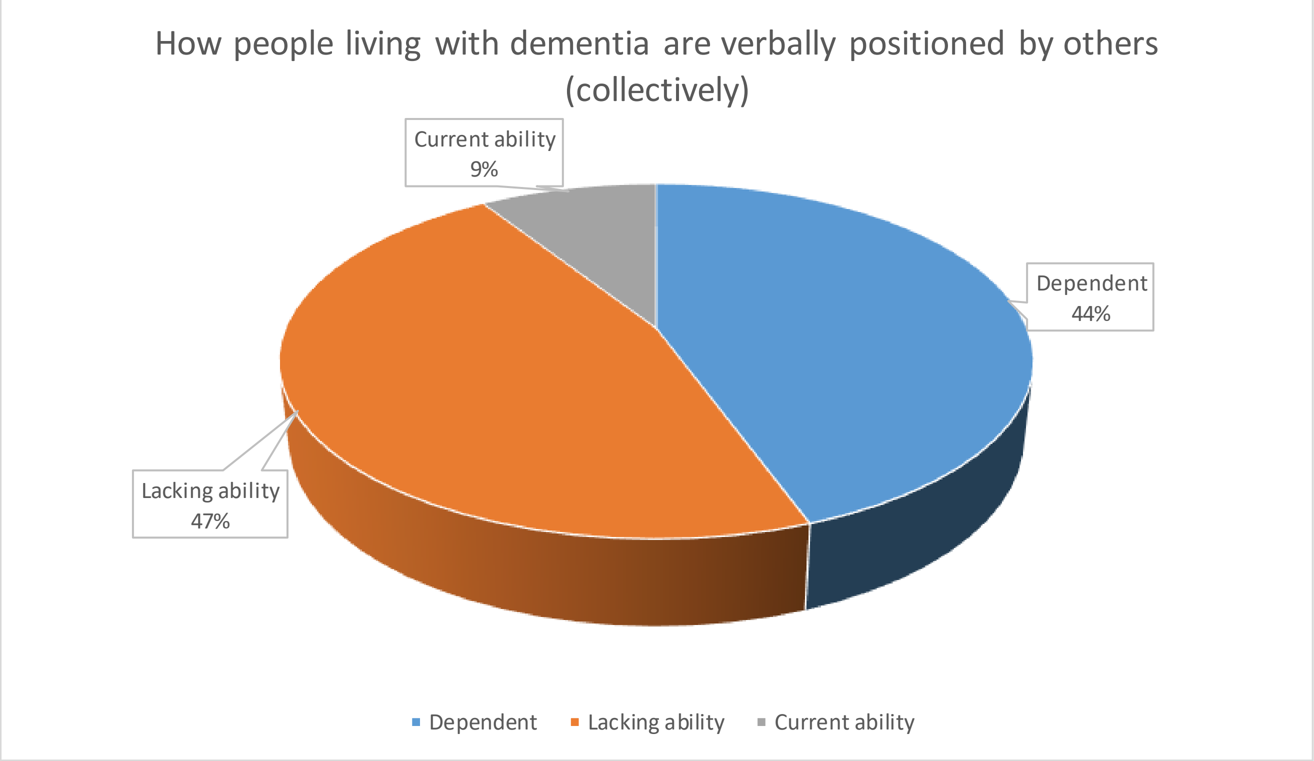
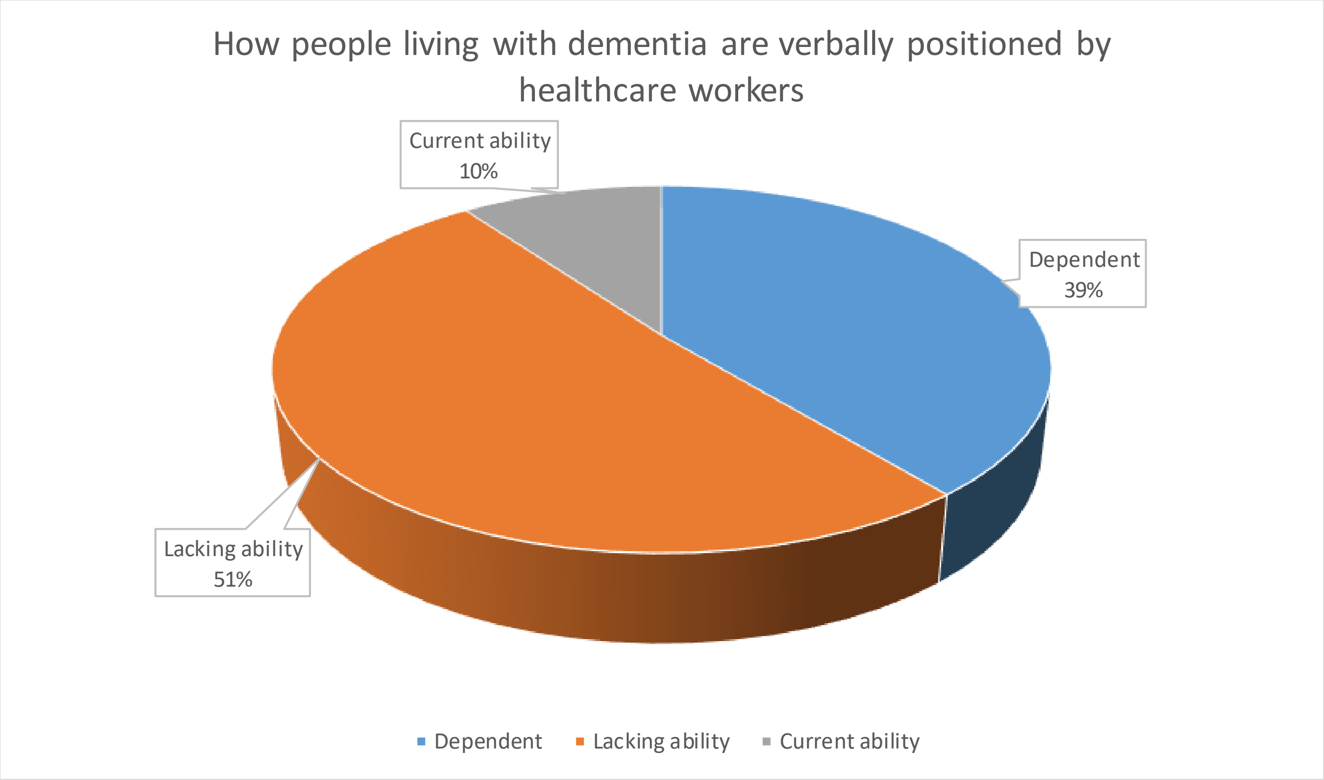


Chart 8: Practical ability: How people living with dementia are verbally positioned by healthcare workers

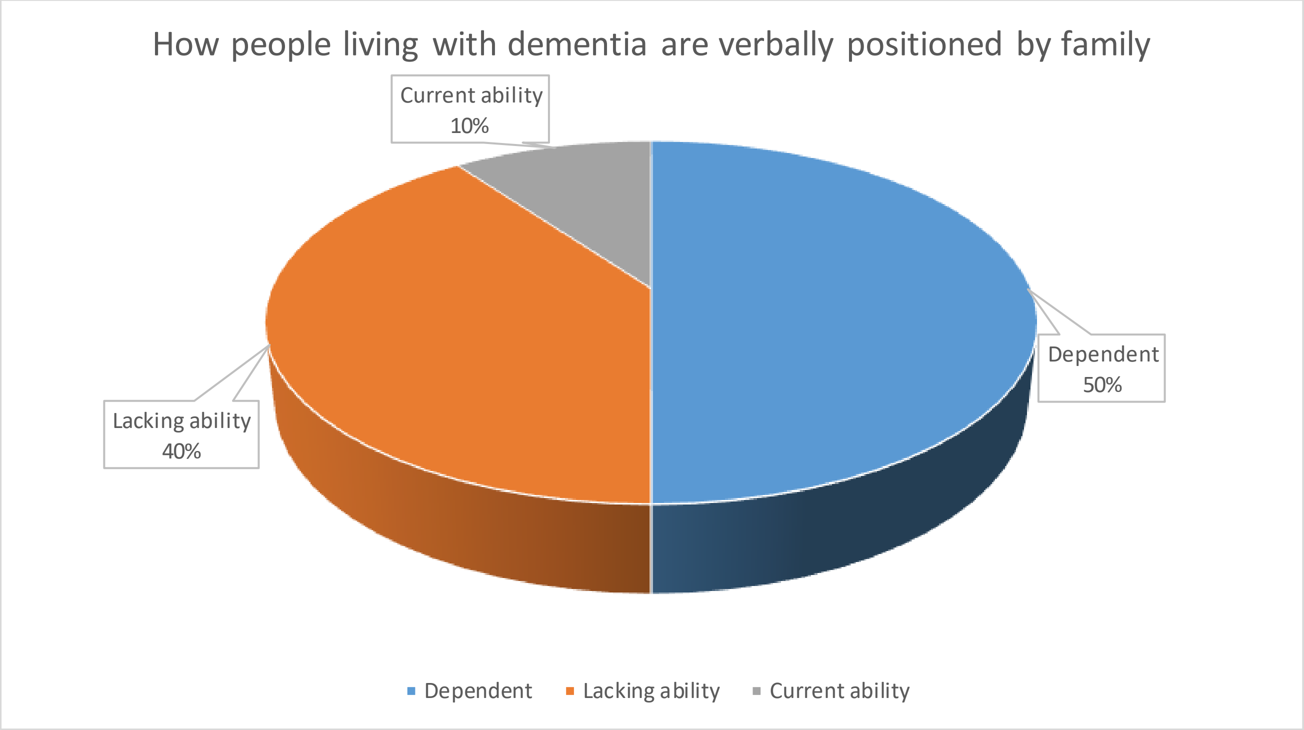


Within familial positioning the occurrence of *no longer capable* and *need help from others* positions is numerically equal although in the latter it is evident that the context of practical ability and the first order positioning by family members results in varying examples of the positions within the subtheme. Needing help is observed within the context of requiring support to maintain a role (Purves, 2010) which may indicate only verbal assistance. The position also indicates a mechanism to support interaction, although not always in a manner that supports equal interactional rights between the person living with dementia and their spouse (Shakespeare & Clare, 2005). Supporting the previous literature's proposition regarding the increased use of malignant positioning as dementia progresses is the example of 'helpless AD sufferer' (Sabat & Harré, 1992) which creates a wholly *dependent* position as an extension of *a patient, not a person* positioning within the *societal standing* theme.

Lacking ability

Lacking ability has the highest occurrence of any sub-theme within the *practical ability* theme. The family is the only group which positions the people living with dementia as *dependent* over *lacking ability* (see Chart 9). This may reflect the positioner acknowledging their role as a helper, rather than focussing on the person living with dementia's abilities.

Chart 9: Practical ability: How people living with dementia are verbally positioned by family



People living with dementia position themselves as *a lesser person* through the use of negative descriptions (e.g. ‘clown’, ‘silly’, ‘stupid’). Other examples by people living with dementia including ‘I can’t talk back to people can I?’ (Cadell & Clare, 2011) and ‘unable to take part in decisions’ (Hedman et al*,* 2012) suggest they may confirm the *lesser person* position created by others. By confirming their own inability to talk back or make decisions the first order *lesser person* position is strengthened by the person living with dementia.

In the positioning by others, examples suggest that the person has less than full membership during conversations with their spouse (Shakespeare, 2004; Shakespeare & Clare, 2005). The healthcare worker example, ‘I’m in charge not you’ (Sabat et al, 2004) acts as a means to demean conversational membership whilst also confirming the person’s practical inability to take charge.

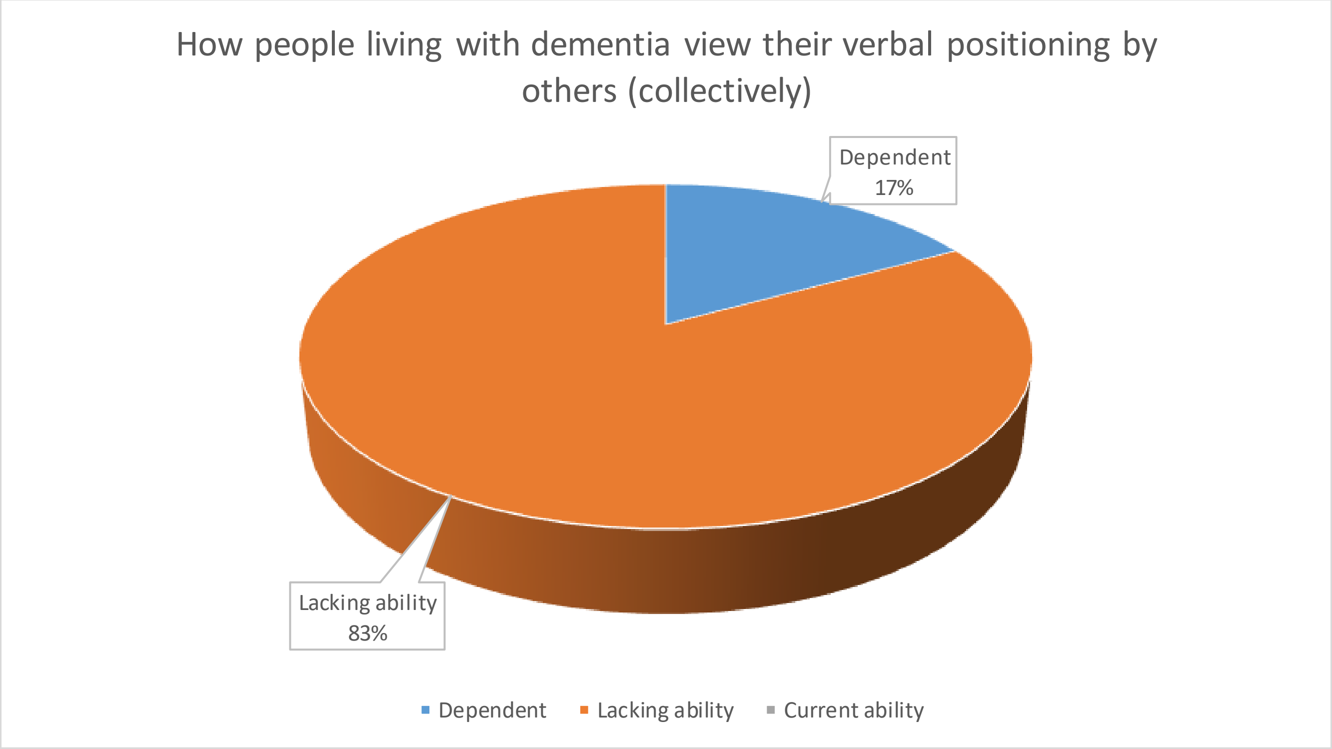
The *unwanted* position occurs more frequently in the positioning by people living with dementia, suggesting a fear of being a burden and therefore being positioned as *unwanted*. The person lack of ability is repositioned as existing practical abilities which have predominantly negative consequences by family members. The person is described as ‘attention seeking’ (Bartlett & O’Connor, 2010) and engaging in tasks ‘inappropriately’ (Shakespeare & Clare, 2005). The overall position of the person *lacking ability* suggests that the decline in practical ability, matched by a desire to continue functioning can manoeuvre them into an *unwanted* position during family talk.

The *unwanted* position is expressed by healthcare workers through the issue of time. The person is described as 'stealing time from other opportunities' (Resnick, 2016) by a medical student who acknowledges that a task will be given precedence over the person themselves. The person as 'stealing time' confirms the fear, of people living with dementia, of 'being in the way' (Davies, 2011). The existence of the *unwanted* position towards people living with dementia directly opposes the presumed role of healthcare workers.

Current ability

The overall theme of *current ability* represents less than a tenth of the positioning by others in the literature (see Chart 7). In comparison the theme is strongly represented in the positioning by people living with dementia (see Chart 6) but does not appear at all in the literature concerning how people living with dementia view their verbal positioning by others (see Chart 10).

Chart 10: Practical ability: How people living with dementia view their verbal positioning by others (collectively)



The people living with dementia's position that they are *better than I was* following the onset of dementia directly challenges many of the negative positions presented in the *practical ability* domain. The limited amount of these examples, however, also suggests that examples of people living with dementia positioning themselves as 'strengthened' (Snyder, 2006) or improved through dementia are uncommon.

The higher occurrence of *current ability* positioning by people living with dementia indicates that people are equally likely to focus on what they are still able to do as well as the abilities they have lost. It is unclear whether people living with dementia have not recognised their functional decline as the *dependent* position created by the family group suggests the person is supported and therefore any decline is negligible for the individual. Equally the predominantly negative positioning by others regarding *practical ability* also suggest that other groups are unable to recognise continued abilities in the face of declining functioning.

In the *dependent* example, ‘unable to use money’ (Roach et al, 2014) an activity was used to position the person as *no longer capable.* Within *an able person* the same mechanism is used to define the person’s current role, including ‘a good cook’ (Batra et al, 2015), ‘I am a lawyer’ (Sabat & Harré, 1992) and directly opposing the family position, ‘able to use money’ (Roach et al, 2014). This latter example illustrates the person’s attempt to impose a second order position following the initial positioning by their spouse. The second order position is a defensive reaction by a person who does not agree with the assessment of their abilities and attempts to address the *dependent* position. The outcome of the second order positioning within this example is an increased defensive position by the person and poorer communication between them and their and spouse. The negative effects of the second order position suggests that the first order position remains dominant. This situation is reflected again in the people living with dementia example ‘I want to be included in conversation’ (Bourbonnais & Ducharme, 2013), suggesting people living with dementia want to influence their own and others positions within conversation. The lack of *current ability* positioning by others, however, suggests that they may have resistance countering the *dependent* and *lacking ability* positions that dominate positioning by others.

3.4.3 Internal values

Negative core

A division between the positioning by people living with dementia and other groups is evident throughout the *internal values* domain. Expressions regarding the desired qualities of a person and therefore the *positive core* of the people living with dementia dominate the positions of the people living with dementia group (see Chart 11) which is juxtaposed by the *negative core* positioning of others (see Chart 12).

Chart 11: Internal values: How people living with dementia verbally position themselves and other people living with dementia

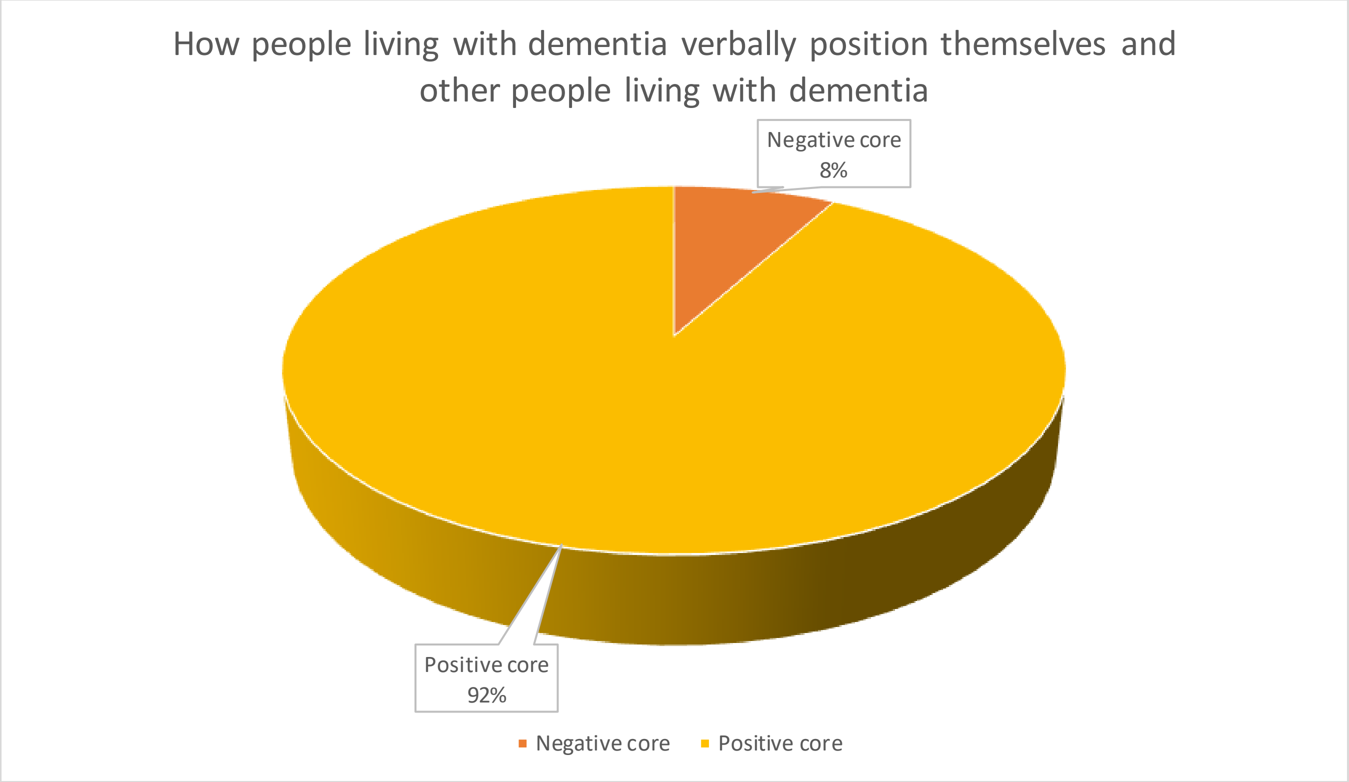
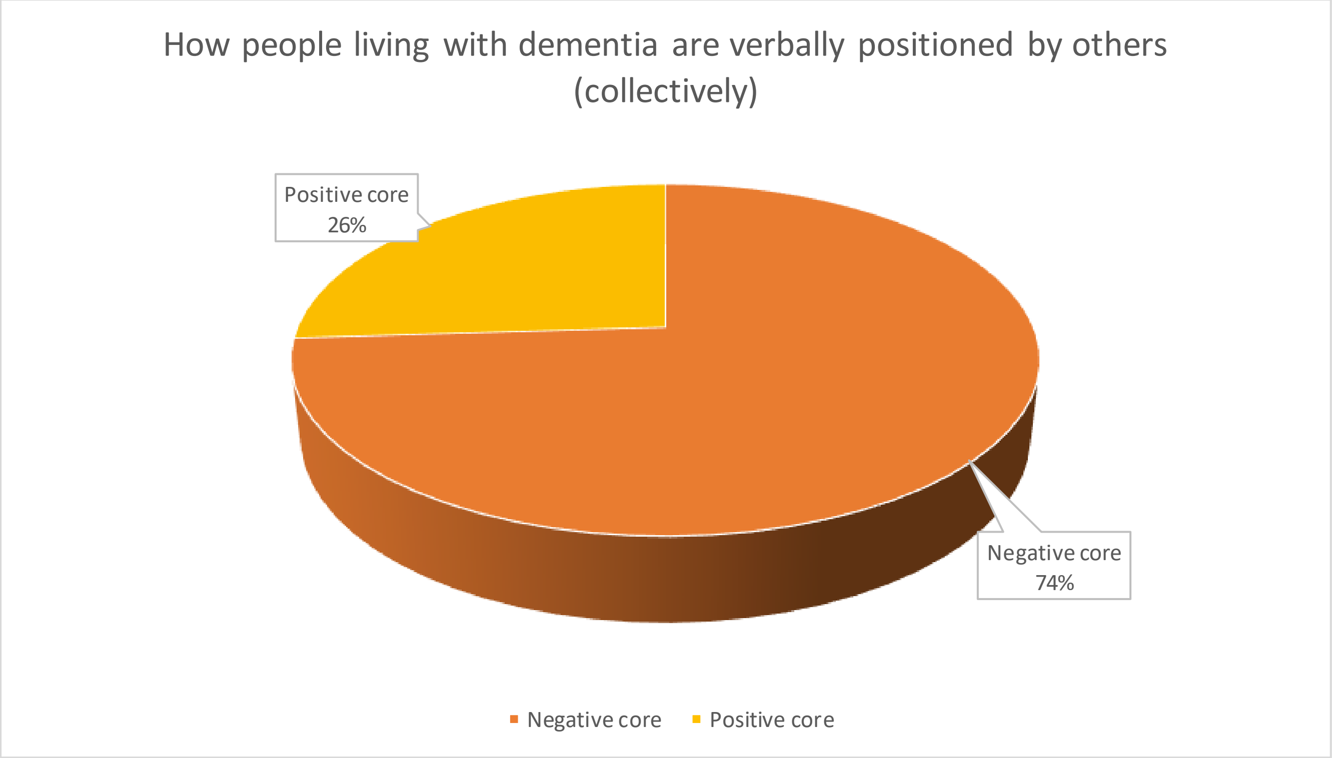


Chart 12: Internal values: How people living with dementia are verbally positioned by others (collectively)



The absence of *internal values* positions in the lay people group suggests they are more likely to occur when there is a personal connection to the person. The occurrence of *negative* and *positive core* positioning is viewed as equal in other groups by people living with dementia although this is not supported by the literature concerning the actual positioning by other groups.

The person living with dementia is positioned as *a person lacking quality* in the examples, ‘foolish’ (Adams & Gardiner, 2005) and ‘hopeless’ (Sabat & Harré, 1992), suggesting that a quality has been lost. Examples such as ‘cruel’ (Robertson, 2015) and ‘self-centred’ (O’Shaughnessy, 2010) suggest that changes in behaviour are driven by the individual’s malignant personality, which represents the *negative core* of the person living with dementia.

Family examples also relate the movement from the person’s *positive core* to being *a person lacking quality.* The movement from ‘fabulous’ to ‘whimpering’ (Walters et al, 2010) suggests a person living with dementia with little resemblance to the person they were before. The spousal example, ‘she doesn’t know how to love me’ (Sikes & Hall, 2016) is an explicitly stated loss of the *positive core.*

The *negative core* creates positions when the person is viewed as a *problem*. A person living with dementia provides the example that they are ‘impeding children’s and grandchildren’s lives’ (Hedman et al, 2012). The person living with dementia acknowledges that changes are having a negative impact on their relationships with family members This position is presented slightly differently in the familial example, ‘she purposefully puts things away in random places’ (Sabat, 2006). The familial example retains the sense of the person impeding the lives of others but does so in an accusatory manner, suggesting that the person wishes to be *a problem*.

The accusatory position of the family member remains in the example, ‘powerful’ (Forbat, 2003). The retention of power could be considered part of a *positive core* but in this example power is undesirable to the family member as the power held by the person living with dementia creates problems for the positioner.

In healthcare worker positioning, people living with dementia are positioned as *a problem* when seeking engagement or purpose through ‘interfering’ (DeMedeiros & Sabat, 2013). The use of *a problem* positioning by healthcare workers does allude to a *negative core* for the person living with dementia although, depending on one’s own viewpoint of dementia healthcare it also creates a negative position regarding the healthcare worker’s practice.

Positive core

The *positive core* position is dominated by examples from the people living with dementia group (see Chart 11) with a 92% occurrence within this group in comparison to 26% in the collective positioning by others (see Chart 12). Examples including 'honest' (Cadell & Clare, 2011) and a 'gentleman' (Saunders et al, 2011) showcase the people living with dementia's vocalisation of their *internal values* and how these are reflected in the perceived identity of the person themselves.

A person living with dementia expressed their affection towards 'family members' (Bourbonnais & Ducharme, 2013) and an awareness of this by family members was observed in the example, 'affectionate' (O'Shaughnessy, 2010). A similar position is found in the healthcare worker example 'People living with dementia care for healthcare worker' (Sellevold et al, 2013). This example opposes the *negative core* position concerning people living with dementia 'interfering' with healthcare worker duties (DeMedeiros & Sabat, 2013). These opposing examples illustrate how the actions of people living with dementia may be given negative or positive positions depending on the individual viewpoint of one person within one group.

Examples within the *resilient* theme describe the person's belief that they have the ability to fight against dementia but the dominance of the *negative core* in other groups suggest that this belief is not shared by others. Although the *resilient* position provides examples of people fighting against the adversity of their diagnosis, examples such as 'not a victim' (Arieli, 2013) also suggest a need to fight against the adversity of other's *negative core* positioning.

3.4.4 An evolving self

Disintegrating self

The domain an *evolving self* was present in the literature throughout each group. The acknowledgement of an *evolving self* although shared by groups within three themes is also displayed by the existence of the *unwanted self* domain which is dominant in the collective positioning by others (see Chart 13) but not present in the people living with dementia group (see Chart 14).

Chart 13: An evolving self: How people living with dementia are verbally positioned by others (collectively)

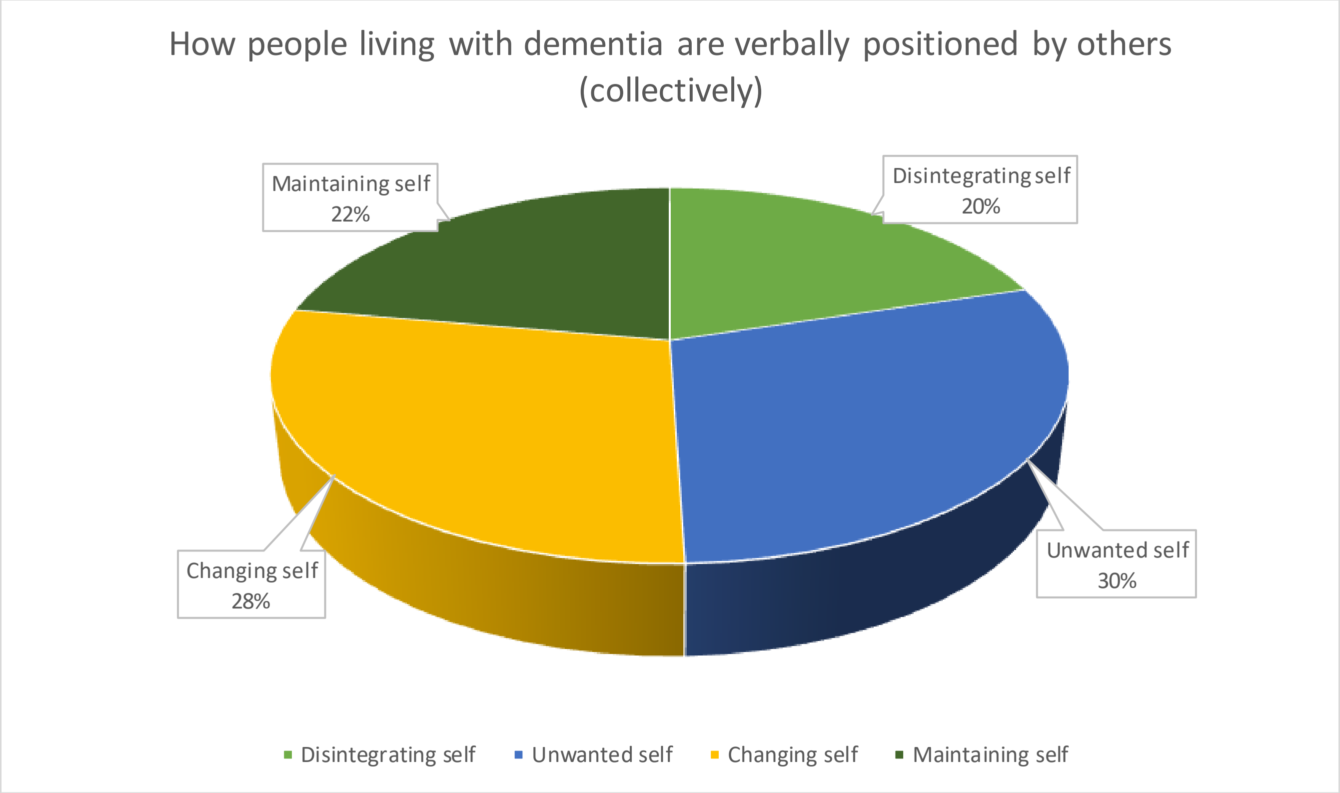
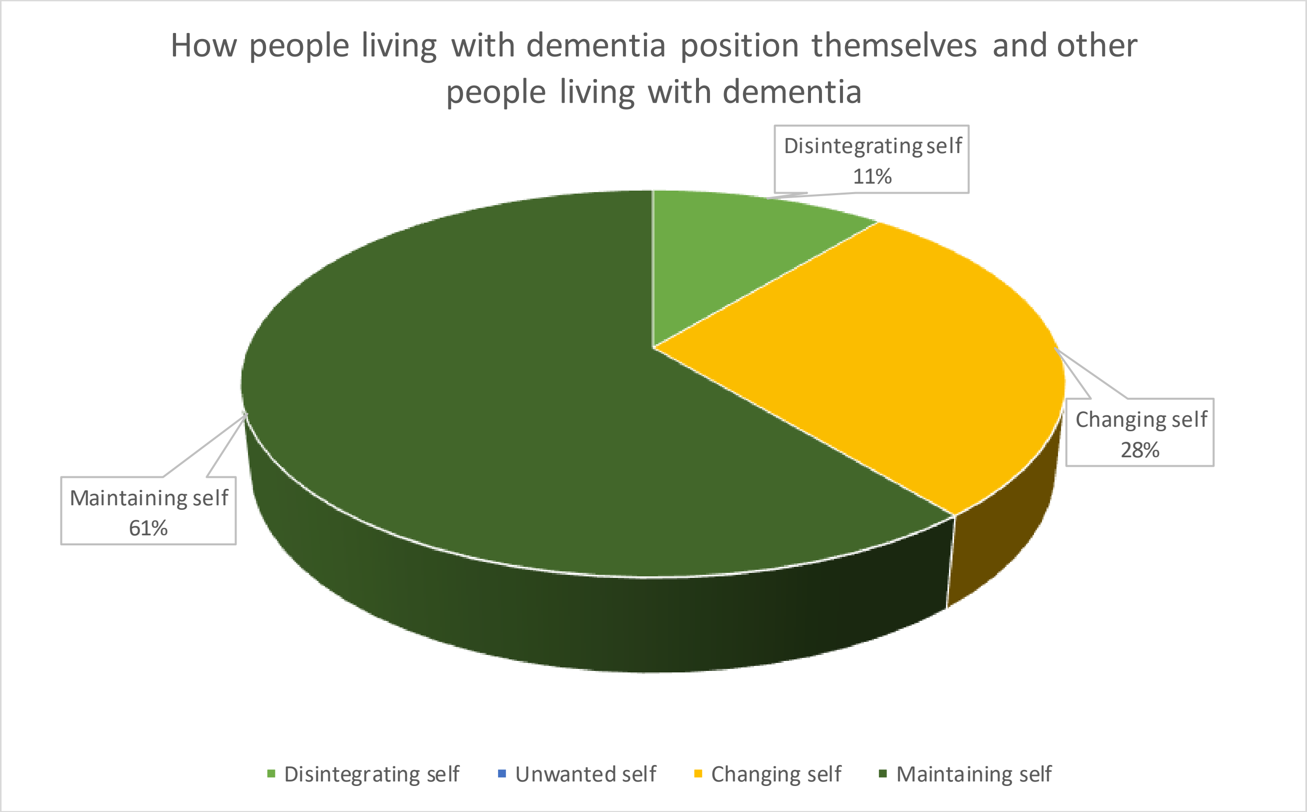


Chart 14: An evolving self: How people living with dementia position themselves and other people living with dementia



The high number of *disintegrating self* positions allocated by family members results in a relatively high occurrence within the overall positioning by others although it is the least prominent subtheme in the overall group concerning *an evolving self.*

The people living with dementia example in the *finished* subtheme, 'given up' (Nowell et al, 2011) suggests that the person has disintegrated as a person, into hopelessness. This is reflected in family member examples, which describe the person as 'gone' (Robertson, 2015; Kjallman-Alm, 2013). The effect of this position on the family member is reinforced when a spouse states that it is the 'end of life as it had been' (Peacock et al, 2016). There is not only a *disintegrating self,* there is also the destruction of a relationship.

Examples within the *finished* subtheme position people living with dementia as no longer present, suggesting life has ended even though the person living with dementia remains physically present. Positioning the person as *finished* culminates in the description of the person as a 'zombie' (Robertson, 2015).

The healthcare worker stating that people living with dementia 'try to hide their symptoms' (Larsen et al, 2015) creates the *disappearing* position by suggesting that although the person has an awareness of their condition and symptoms they are no longer able to impose their own sense of self.

Maintaining self

There is a high occurrence of *maintaining self* (see Chart 14) positions in the literature from the people living with dementia group compared to a 22% occurrence in the overall group positions (see Chart 13). A disparity does exist between other groups and healthcare workers who have a 47% occurrence of *maintaining self* positions within the *evolving self* domain (see Chart 15). This is not reflected in how people living with dementia view their positioning by others as there are no occurrences of *maintaining self* within this group (see Chart 16).

Chart 15: An evolving self: How people living with dementia are verbally positioned by healthcare workers

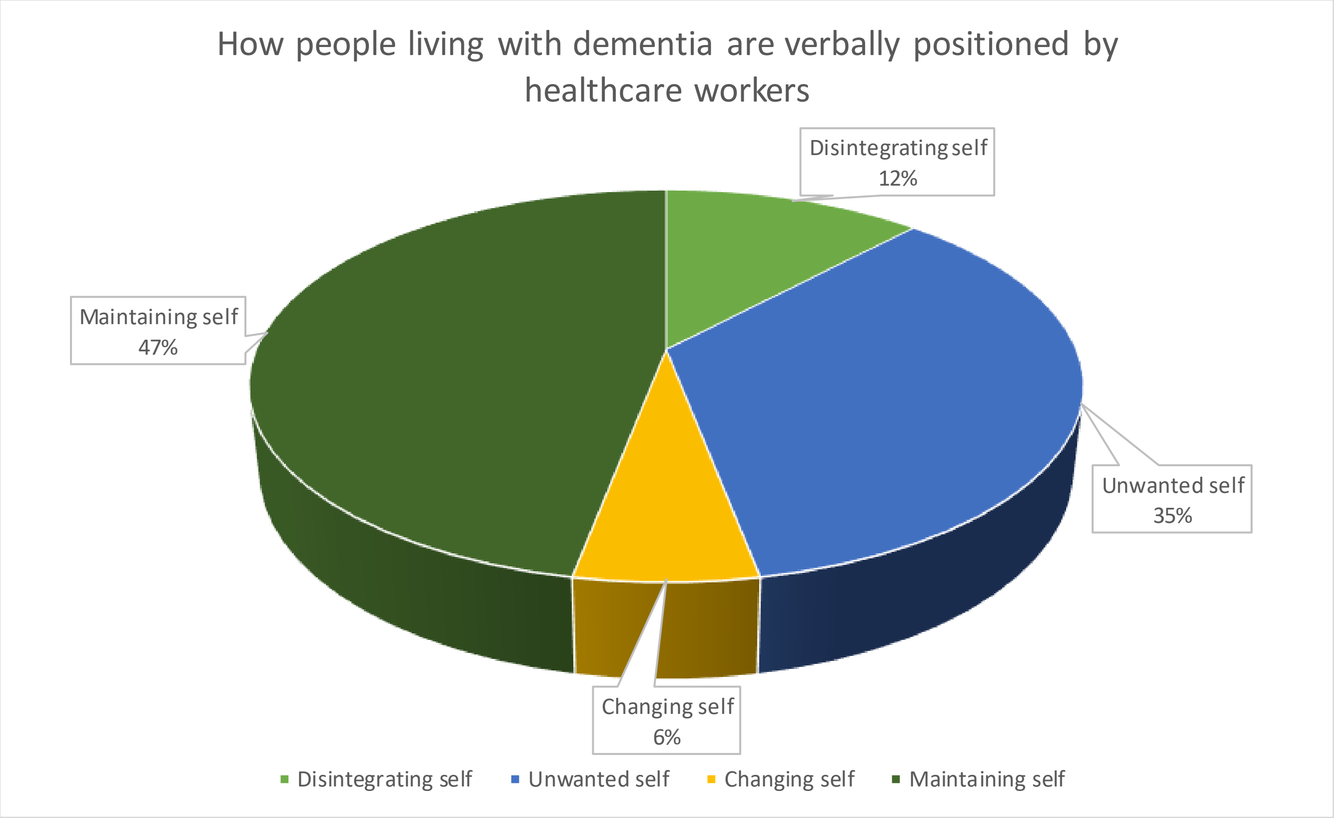
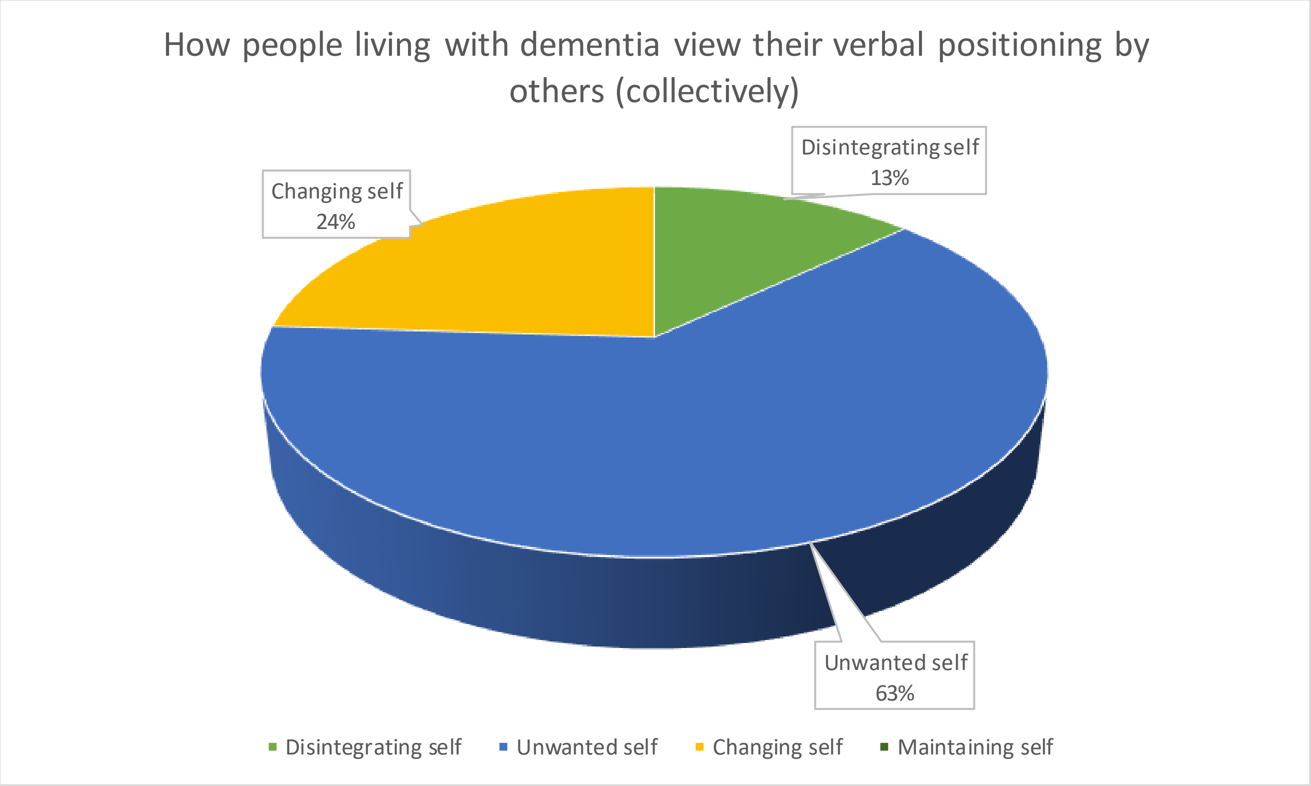


Chart 16: An evolving self: How people living with dementia view their positioning by others (collectively)



A *normal* position, despite being individually unremarkable, appears to be a desired position for people living with dementia. Although examples including ‘average’ (Clare & Shakespeare, 2004) and ‘ordinary’ (Godwin & Poland, 2015) initially appear undistinguished, their desirability is evident when compared to the *disintegrating self* examples of ‘zombie’ (Robertson, 2015) and ‘a shell of his former self’ (Walters et al, 2010).

Selfhood is addressed in positions concerning *the same person*. The examples from people living with dementia reflect a belief that selfhood is retained following diagnosis. The direct statements ‘I’m still me’ (Clare, 2005; O’Sullivan et al, 2013) and ‘I’m still the same old thing’ (Cadell & Clare, 2011) are uncomplicated and explicit in their positioning. Direct quotes regarding the person living with dementia being the ‘same person’ (Perry & O’Connor; Walters et al, 2010) are also present in examples from the family member group.

The relatively high occurrence of the *maintaining self* position in the healthcare worker group suggests that it is not necessary to know the person before their diagnosis to appreciate the selfhood of the individual following diagnosis. The example of ‘selfhood recognised’ (Kelly, 2010) acknowledges the maintenance of the self whilst being coetaneous with the healthcare worker’s responsibility to uphold the selfhood of the person living with dementia.

Not like other people living with dementia positions occur only in the people living with dementia group. Although these examples are numerically limited they do offer insight into how people living with dementia may position themselves away from other people living with dementia. ‘Daft’ (Langdon et al, 2007), ‘aggressive’ and ‘negative behaviours’ (Cadell & Clare, 2011) are used by the positioner to separate themselves from these positions but at the same time they reinforce the malignant positioning of people living with dementia in general. These examples perpetuate the malignant positioning that the individual person living with dementia is attempting to eradicate for themselves.

Changing self

Positions concerning the *changing self* suggest that although the person living with dementia remains physically present they are no longer *the same person* that featured in the *maintaining self* theme. *Changing self* is the dominant theme in the positioning by family members (see Chart 17) although its overall occurrence is relatively similar to its occurrence in the people living with dementia group (see Chart 14). The high percentile occurrence of *changing self* positions within the lay people group (see Chart 18) is symptomatic of the limited results concerning lay people and the domain, *an evolving self.* As with other domains this limited information may be due to the lack of a relationship between the lay person and people living with dementia which would inform the domain but is also due to the limited amount of studies concerning lay people's verbal positioning.

Chart 17: An evolving self: How people living with dementia are verbally positioned by family members

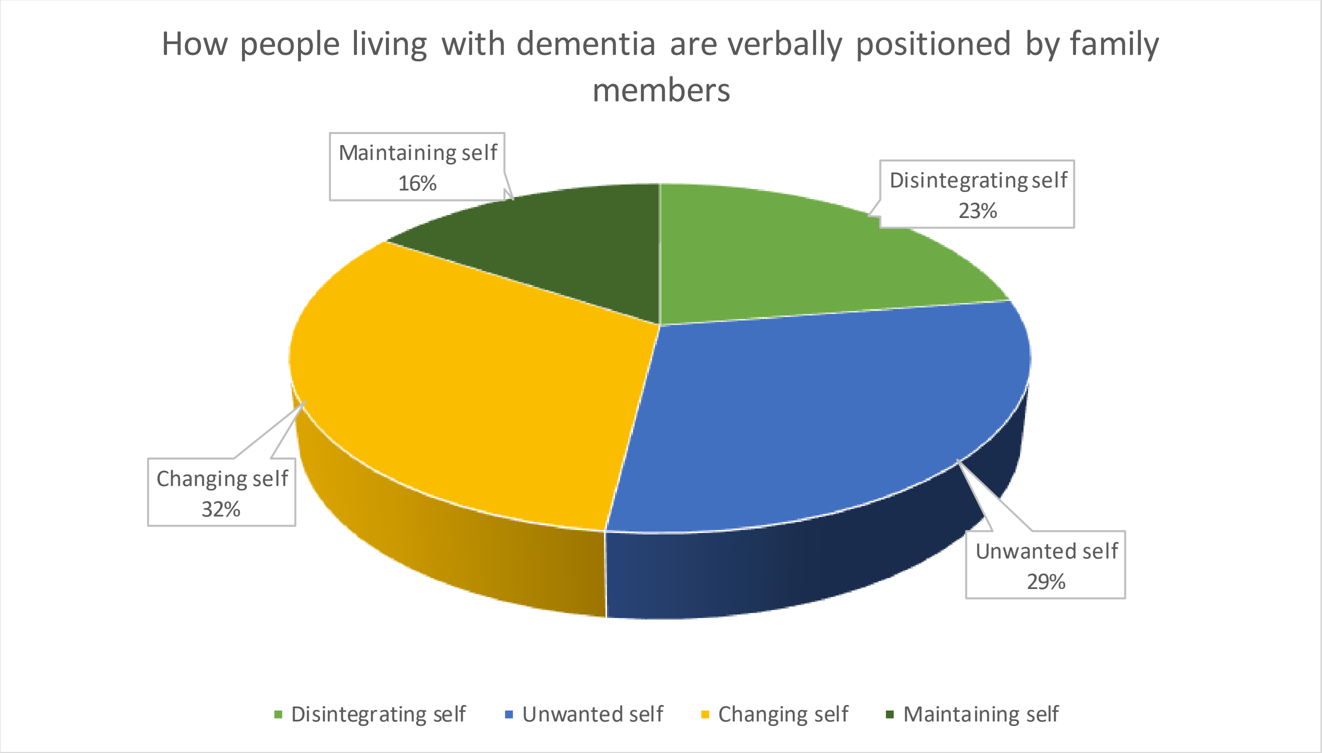
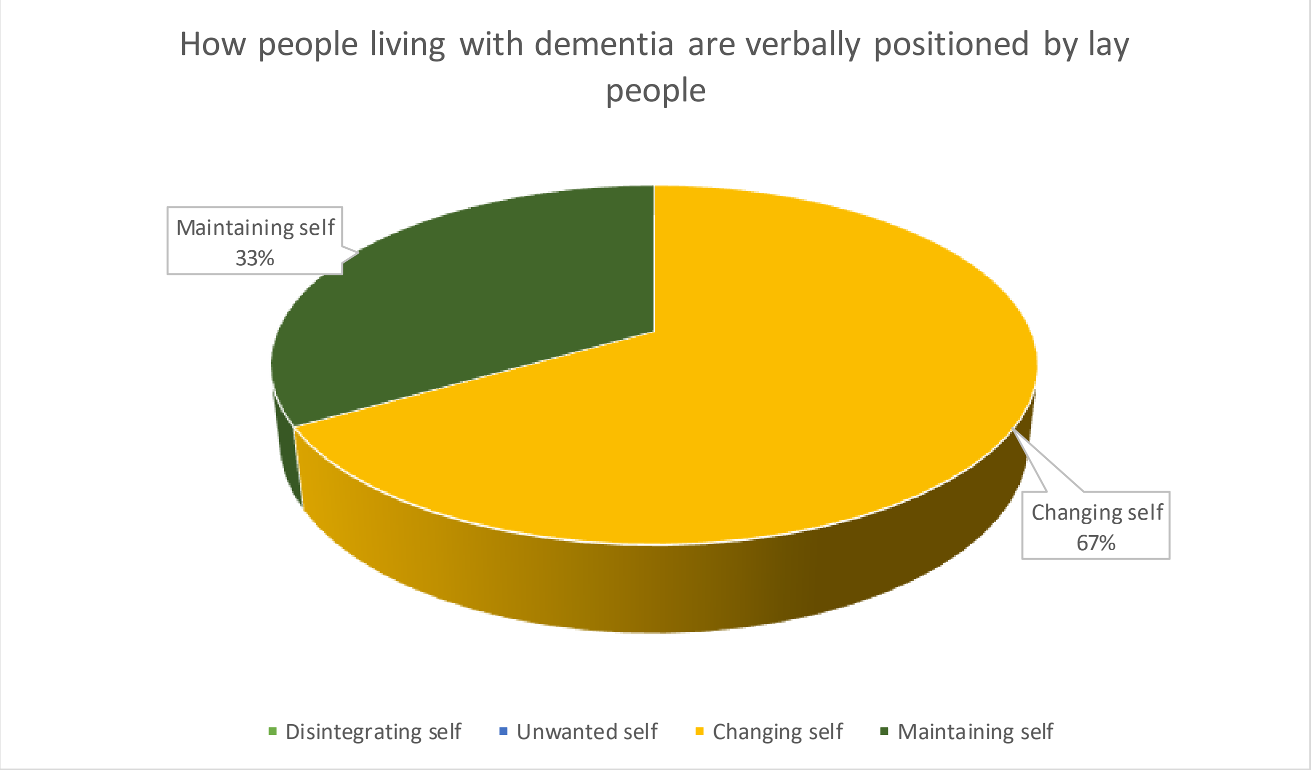


Chart 18: An evolving self: How people living with dementia are verbally positioned by lay people



The two subthemes offer different perspectives of the *changing self. A different person* suggests that selfhood still exists but not the pre-diagnosis self. *More than a diagnosis* acknowledges that there have been changes in the person but that their existence should not be defined by dementia.

'I'm not the same person' (Cadell &Clare, 2011) is a person living with dementia explicitly contradicting 'the same person' position from the same study, which informed the *maintaining self* theme. This is an acknowledgement that the reality of the person is altering and although changes may appear small there is a sense of being *a different person* to before. Opposition to *the same person* subtheme is also present in the family member examples, 'seeming normal, but not being the same' (Robertson, 2013).

Changing self positions within the family member group are predominantly related to the presentation of the person living with dementia although other family members support the subtheme by stating how they feel the altered selfhood of the person has affected their relationship. The statement 'you obviously don't feel about him like you used to feel' (Walters et al, 2010) acknowledges a *changing self* but also a changing family relationship. In the same study the perception that the person looks the same as before but is actually different is reflected as graphic fantasy in 'they switched someone's, someone else's mind with his'.

Examples of *more than a diagnosis* are limited although 80% of all entries occur in the people living with dementia group. Despite an awareness of the *changing self* the person living with dementia does not believe that their diagnosis now dictates their selfhood, stating that 'dementia is not who I am' (Batra et al, 2015).

Unwanted self

Unwanted self is the dominant theme regarding how people living with dementia view their positioning by others throughout the domain of *an evolving self*.

It is also the dominant theme in the overall positioning by others (see Chart 13). Family members provide the majority of examples concerning the *unpleasant* subtheme. Family member positions are created through powerful statements including 'liar' (Adams & Gardiner, 2005) and 'utter bitch' (Sikes & Hall, 2016). This positioning is supported by the family member who feels that the person's behaviour is deliberate and controllable (Walters et al, 2010). This creates the *unpleasant* position by suggesting that the person has the positive attribute of insight but behaves negatively. This is extended as family members state they now hate the person living with dementia.

A healthcare worker states that it would be undesirable to stop and talk to a person living with dementia (Resnick, 2016). Unlike the familial examples this is not an expression of distaste towards one individual but rather the creation of a universally *unpleasant* position for all people living with dementia.

The person as dysfunctional or irrationally hostile informs the *don't go near* subtheme. Family members and healthcare workers portray people living with dementia as unpredictable and possibly hostile 'for no reason' (Sabat, 2008). Healthcare workers using the term 'challenging behaviour' (Resnick, 2016) to explain the person's actions indicates a dismissal of what the behaviour may tell us and an immediate acceptance that the behaviour is *unpleasant* to the positioner. Behaviour is not regarded as a sign of distress but a problem for the healthcare worker. Concerns about behaviour and the lack of understanding regarding its meaning may also inform family member's embarrassment about being seen or associated with the person living with dementia (Offord et al, 2006; Kjallman-Alm, 2013).

For people living with dementia, it is the subtheme of *maintaining self* that dominates an *evolving self,* whilst the likelihood of malignant positioning is increased by the dominance of the *unwanted self* in other groups.

3.4.5 Control over life

No control

No control is present in the people living with dementia group but is the least prevalent position for this group throughout the *control over life* domain (see Chart 19). There is a clear awareness of this positioning on behalf of people living with dementia as it dominates the view of how people living with dementia are positioned (see Chart 20). This view is ratified as the theme is dominates the domain in other groups (see Chart 21).

Chart 19: Control over life: How people living with dementia verbally position themselves and others

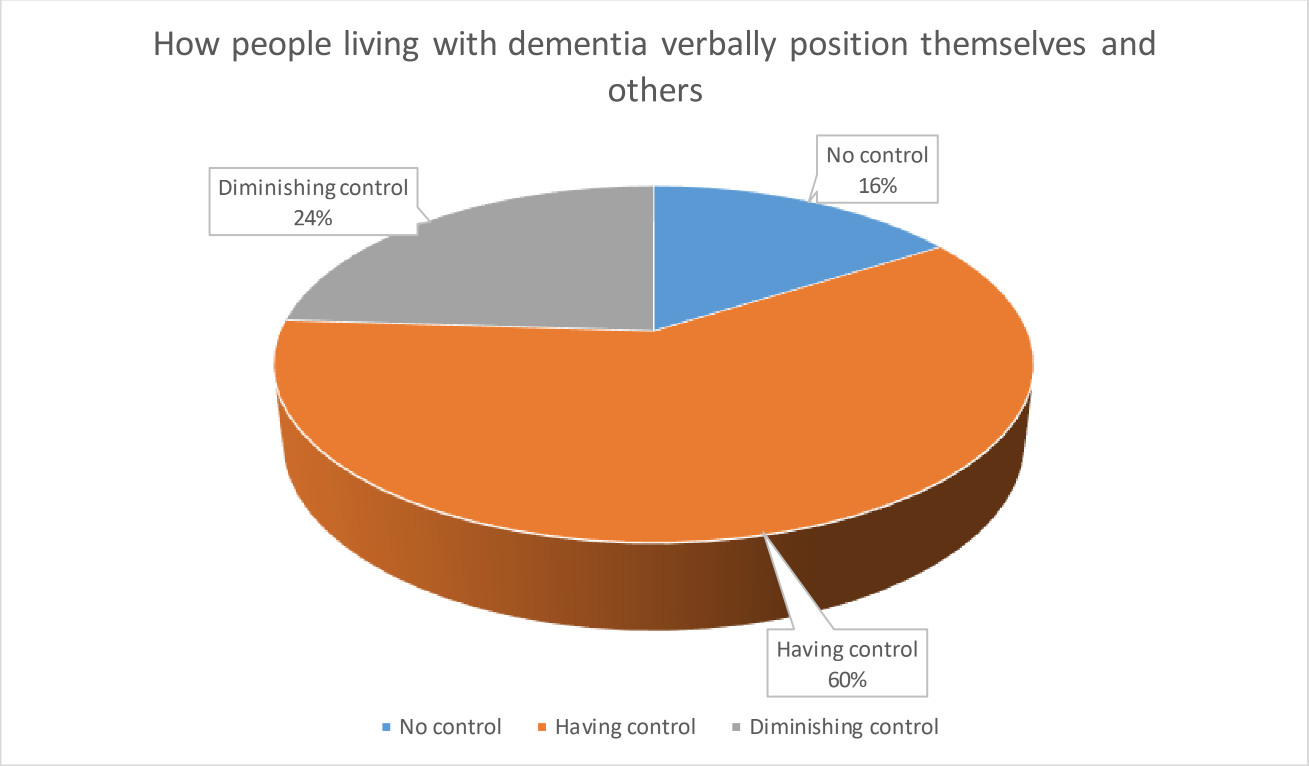


Chart 20: Control over life: How people living with dementia view their verbal positioning by others

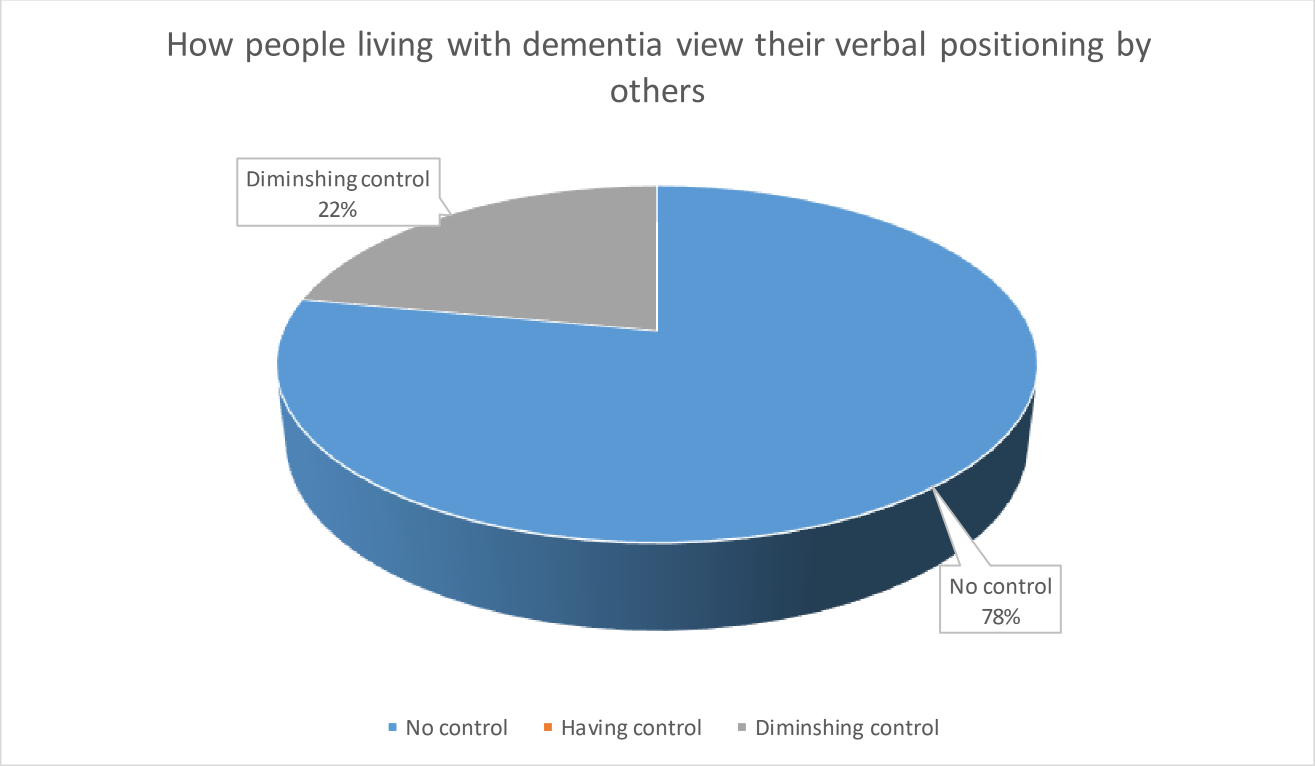
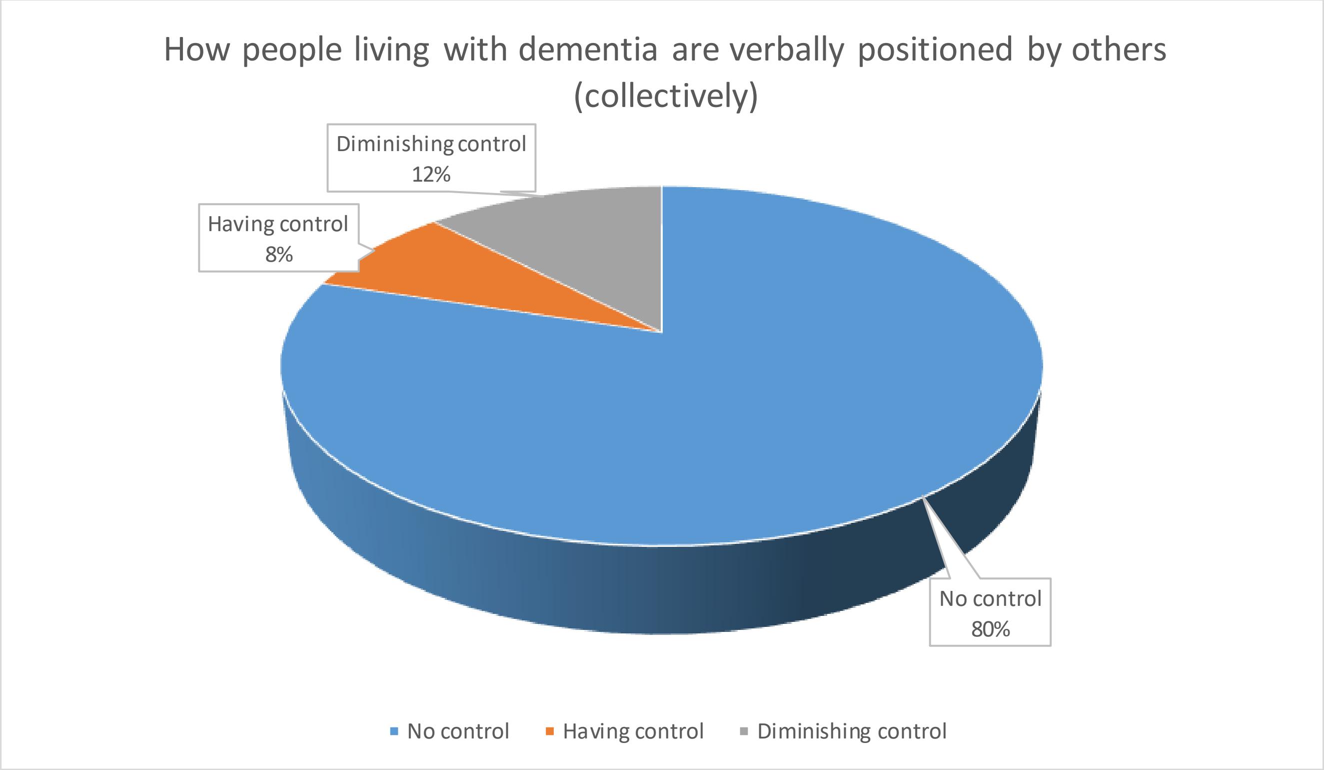


Chart 21: Control over life: How people living with dementia are verbally positioned by others (collectively)



The positioning by people living with dementia related to the *don't know what's going* on subtheme is not dissimilar to that of other groups with examples tending to focus on an absence of competence and the presence of confusion. Colloquial language such as 'crackers' (Langdon et al, 2007) is used when people living with dementia describe how they view how others position them whilst the term 'crazy' is present in other groups and represents the only entry in the how people living with dementia view the positioning by lay people group.

Second order positioning is observed when a person living with dementia creates a positive position for themselves by stating 'my bike is my freedom', suggesting a retention of control in their life (Steeman, 2007). The family member counters by responding that 'her freedom' is 'aimless riding'. Although the family member creates a second order position to place the person living with dementia in the *don't know what's going on* subtheme it is not evident that this is an accurate reflection of their control. Whether the destination is purposeful, in the opinion of the family member, is irrelevant to the first order position.

An *unpleasant* position described behaviour as deliberate and controllable whilst an example from the *don't know what's going on* subtheme within the same study considers that the person 'can't help it' (Walters et al, 2010). Although the latter example simplifies the behaviour, it may be preferable for family member to view behaviours indicative of *no control* rather than condemn the person as *unpleasant.*

Familial positioning tends to suggest that the person has *nothing to offer* due to an inability to converse or because their perspective is not wanted (Adams & Gardiner, 2005). If a person's lack of capacity is informing the family member's verbal positioning, this dominates decisions and they are not taken seriously during conversations (Adams & Gardiner, 2007). However, examples regarding how people living with dementia view their positioning by others concern being ignored and therefore it is unlikely that this is related to a lack of capacity as people living with dementia are reporting this positioning themselves. People living with dementia are aware of negative positioning by others but this does not prevent other groups positioning them as having *nothing to offer*.

Having control

The subtheme *having control* is dominant in the people living with dementia group (see Chart 19) but there are no occurrences within the group regarding how people living with dementia view their positioning by others (see Chart 20). Examples of *having control* are also limited in other groups with an overall occurrence of 8% (see Chart 21) whilst there are no occurrences in the lay people group.

The high frequency of *having control* positions within the people living with dementia group could be an outcome of the literature predominantly containing narratives from people living with dementia in the earlier stages of a dementia syndrome. However, this does not support the dearth of literature in other groups regarding the *having control* position or explain why others may be reluctant to engage in this type of positioning.

The adage that all behaviour has meaning is reflected within the subtheme *master of own destiny* as the person living with dementia positions themselves as being able to control their future through their behaviour. Suggestions that the person living with dementia will choose to cooperate with another person if they are treated as a person or as independent and choose to be uncooperative if seen as dependent or depersonalised (Small et al, 1998) support the *master of own destiny* position through the recognition that behaviour may allow the person living with dementia to influence their future.

The person screaming because their needs are not met (Bourbonnais & Ducharme, 2013) is one familial example in the *know own mind* subtheme that does suggest an acknowledgement of the person's behaviour having meaning. Although the behaviour of the person is not considered desirable, the family member acknowledges they retain the ability to know what they want to happen to them. People living with dementia also acknowledge a continued ability and insight to recognise one's own desires and dislikes (Bourbonnais & Ducharme, 2013; Batra et al, 2015).

Competency within the people living with dementia group is not exclusively viewed as a continuation of current abilities but also a recognition that the person is able to develop new skills (Preston et al, 2007) whilst both the people living with dementia and family groups are able to acknowledge a sustained intelligence in people living with dementia (Sabat & Harré, 1992; Walters et al, 2010).

Diminishing control

Although examples in this subtheme do acknowledge that there has been a change in the control or capacity of people living with dementia it does not contain the more nihilistic approaches that were observed in other sub-themes. Numerically it is a lesser subtheme for all the positioning groups. Within the positioning by people living with dementia it is dominant to *no control* (see Chart 19) but in all other groups, except for lay people which has no occurrences, it is dominant over *having control* (see Chart 22 and 23)

Chart 22: Control over life: How people living with dementia are verbally positioned by family members

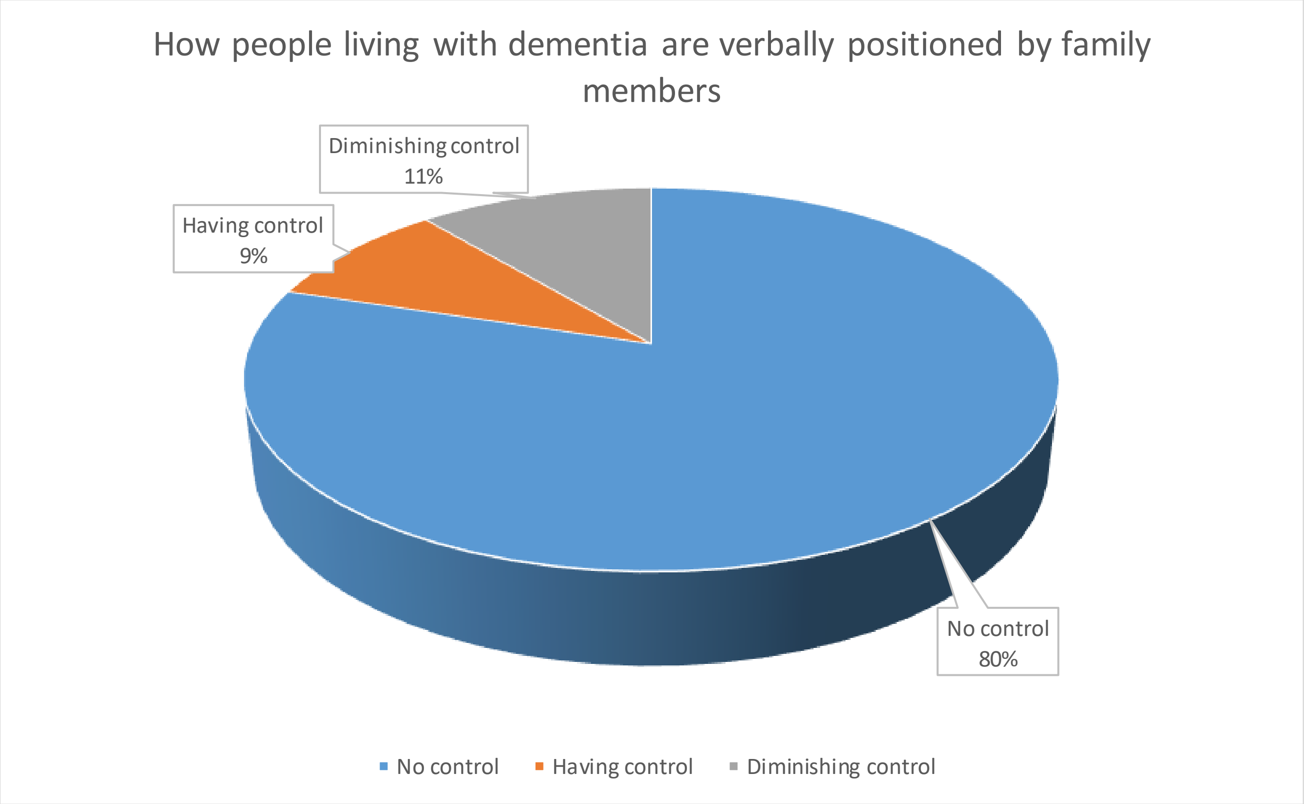
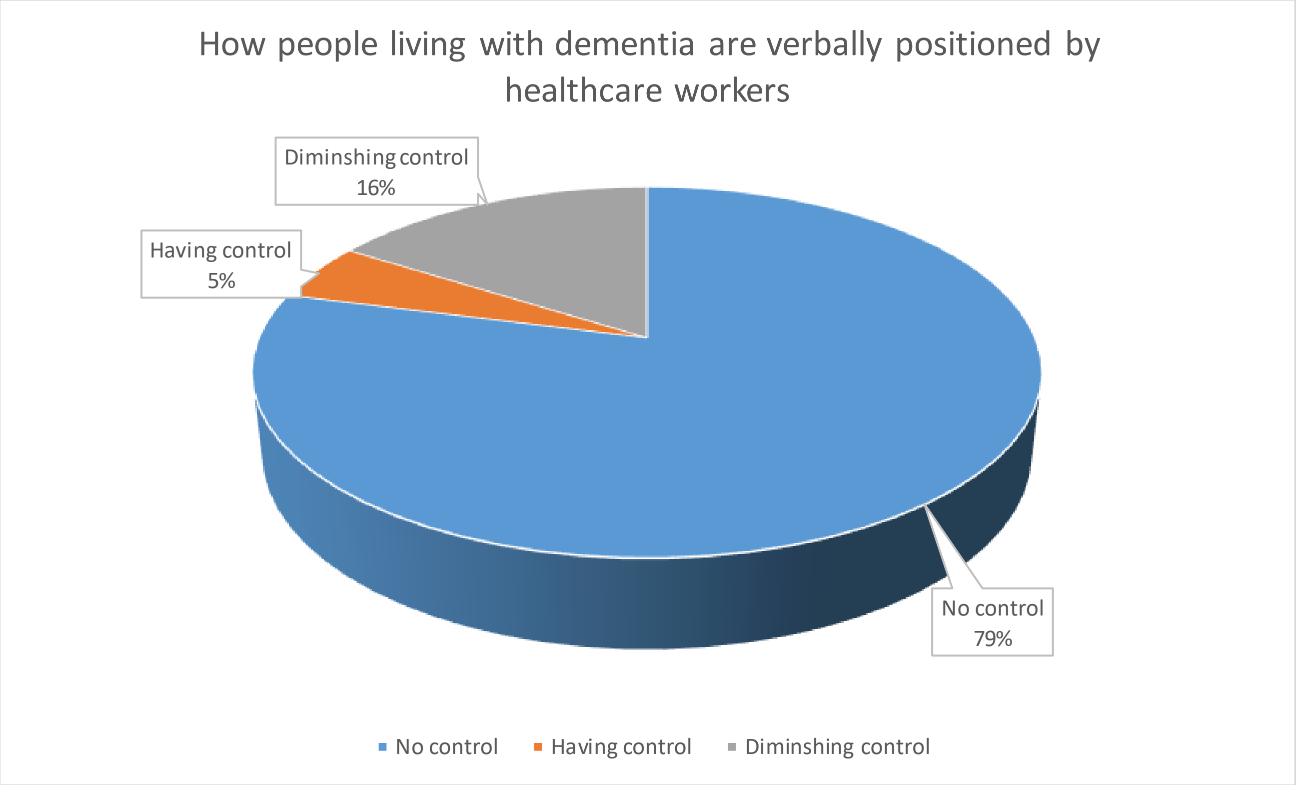


Chart 23: Control over life: How people living with dementia are verbally positioned by healthcare workers



Not well positions are a contained in the positioning by people living with dementia or how people living with dementia view their positioning groups, suggesting that something is not quite right or that control and capacity are becoming lost. The person living with dementia stating 'you don't see me on my bad days' (Bartlett & O'Connor, 2010) represents a person acknowledging their control changes daily or even within situations. A similar position is taken in the *losing control* subtheme when the person living with dementia describes themselves as being like 'Jekyll and Hyde' (Merrick et al, 2013).

Other examples in the *losing control* subtheme are predominantly in the people living with dementia group. Although some examples do concern a lack of agency or independence (Merrick et al, 2013; Batra et al, 2015) others, similar to the Jekyll and Hyde example, suggest a recognition by the person that although control or capacity have not been completely lost changes are beginning to be observed. This is observed in feelings of being 'not with it' (Nowell et al, 2011) or the acknowledgement that although one may have behaved badly in the past the person no longer feels they are able to control when this behaviour occurs (Godwin & Poland, 2015).

Consultation

Due to the complexity of scoping reviews there remains a potential risk that widely different interpretations could be made of the same literature (Davis et al., 2009). Both the theming and narratives provided in this review for the verbal positions within the literature may be challenged. Arksey and O'Malley (2005) suggested that consultation during a scoping review was recommended but optional. To limit the accusations of negligible rigour in scoping reviews, Levac, Colquhoun and O'Brien (2010) stated that consultation was not optional but essential. Throughout the scoping review, the process of defining positions and the construction of the narrative has been overseen by the PhD supervision group. This has provided the review with an accuracy that would not have been feasible as a lone reviewer. Likewise, it should also be observed that scoping reviews are not a final product in their own right (Grant & Booth, 2009). This scoping review has been conducted to provide evidence that verbal positioning of people living with dementia is currently incongruent with how people living with dementia position themselves.

3.5 Synthesis

The scoping review was completed to identify whether the subject justified intervention through empirical research. Prior to the synthesis of all themes, discussions concerning individual domains were completed. These are included in Appendix 9.

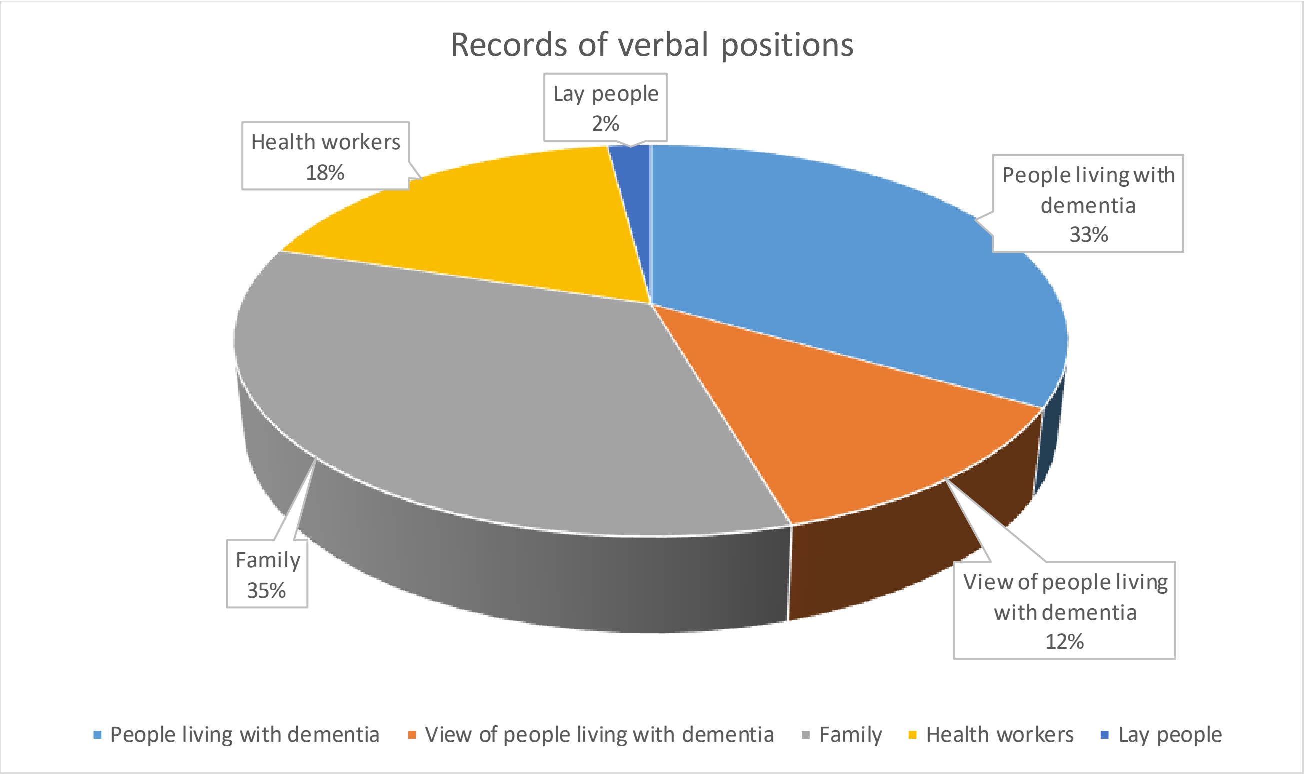
The review had two overarching agendas:

- The positioning by others.
- The positioning by people living with dementia (the desired position)

The positioning by others

It was evident that verbal positions allocated by people living with dementia were significantly different to other groups. The verbal positions taken from the literature were dominated by those of people living with dementia and family members (see Chart 24)

Chart 24: Records of verbal positions by group



Although areas of positioning had similar occurrences between people living with dementia and family members (e.g. the theme of *changing self,* 28% v 32%) there was a higher incidence of verbal positions that suggested a disparity between the groups (e.g. the theme of *maintaining self,* 61% v 16%). This variation does indicate a disagreement between the groups regarding the verbal positions given to people living with dementia although this lack of alignment does not dictate the allocation of negative or malignant positions. *Different person* positions could indicate an acceptance of the *changing self* rather than a denial of who the person living with dementia wants to be. The positions that everything's changed (Robinson, Clare, & Evans, 2005) is shared by both the person living with dementia and the family member. Rather than the denial of a preferred *an evolving self* position, the shared position allows both parties to acknowledge that dementia does alter the lives of all those affected.

The shared position is uncommon with incidents of disparity more regularly displayed. The higher frequency of *lost humanity* and *reduced rights* positions in the family group indicates verbal positions that are unlikely to have been produced through malice but equally, are likely to represent malignant positioning. The perlocutionary force of malignant positioning is malignant social psychology. Malignant social psychology describes actions taken by 'healthy' others that undermine the personhood of the person living with dementia despite the instigator having no malicious intent (Kitwood, 1997). The objectification observed in these themes is indicative of family members engaging in malignant positioning of people living with dementia. Although spouse's have been observed to acknowledge the subjective self of the person living with dementia they also refer to the person living with dementia in objective terms (Golden & Lund, 2005).

One source of verbal positioning suggested that couples who are experiencing the early stages of dementia report being as satisfied with their lives as the general population (Davies, 2011) but it was not possible to review whether this altered the verbal positioning by these couples due to the lack of demographics available for other positioning examples. Likewise, whilst sources also suggested that younger relatives are less likely to uphold the 'still the same' person position when a parent has dementia (Sikes & Hall, 2018) this was also difficult to assess outside of the original piece of research.

The lack of verbal positions provided by lay people has also resulted in the scoping review providing little insight into this group. The lack of lay people positions reflects the research interest in people with conditions, family members and those who professionally care for them. Although there is little in the existing literature regarding lay people this does not distinguish their importance to this thesis. The lack of information is a major gap in the research, particularly as lay people have a significant influence on the social psychology of wider society. Although there is disparity between the verbal positions provided by lay people in comparison to people living with dementia, the relatively small number of positions prevents the scoping review from providing conclusive data and is therefore an area requiring further exploration.

Healthcare workers shared the disparity of other groups in comparison of their verbal positioning to people living with dementia. In comparison to family members, however, there was a significantly higher occurrence of *maintaining self* positions in the healthcare worker group (47% to 16%). This outcome was surprising as source material had suggested that healthcare workers were actually more likely to stereotype people living with dementia due to having a relationship with the person through a social construction of dementia (Purves, 2010). The high occurrence of *maintaining self* positions within this group may indicate that assumptions of stereotyping by healthcare workers are inaccurate although a positive bias may also be indicative of how verbal positions were captured during individual pieces of research.

The outcome of collecting how people living with dementia view their verbal positioning by others illustrated that people living with dementia are often aware of the disparity between their own and other's positions. There are no records of people living with dementia providing verbal positions that contribute to the *reduced rights/roles* theme yet these positions have a 29% occurrence in the *societal standing* domain in regards to how people living with dementia view the positioning of others. This provides further justification for the thesis to explore how people living with dementia may influence the verbal positioning of others for although the literature has provided evidence that people living with dementia are aware of the positioning of others it does not provide evidence of alternative positions when this deviance has been explained to the positioner.

In review of the overall positioning by others in comparison to people living with dementia the greatest indicator of disparity is the existence of sub themes and themes in some groups that are not present in others:

- No incidents of *better than I was* positions in the positioning by others or how people living with dementia view their positioning by others.
- No incidents of *having control* positions in how people living with dementia view their verbal positioning by others. *Having control* positions did occur in the positioning by others but their absence in this group suggests that they were not experienced by people living with dementia in the literature and could represent positive positions for people living with dementia that are not publicly shared
- No incidents of *a person lacking quality* in positioning by people living with dementia.
- No incidents of *unwanted self* in positioning by people living with dementia. The position did have the highest occurrence within the domain for how people living with dementia view the positioning of others, again suggesting that although people living with dementia are aware of the position they do not use it themselves.
- No incidents of reduced *rights/roles* in positioning by people living with dementia.

These represent the most significant indications that there is a considerable deviance between the positioning of others and people living with dementia. It may be reassuring to accept that positions considered malignant towards a person living with dementia may happen without malicious intent but the existence of the *reduced rights/roles* theme provides greater concern. As the literature often provides a verbal position without a narrative structure it is difficult to ascertain whether examples in this theme were created without malicious intent, however, the perlocutionary effect of such positions provides a reality more dangerous than the existence of malignant social psychology practices. Locutions that create a position of people living with dementia having less rights than other people risk creating a perlocutionary reality that allows both verbal and physical abuse to occur to people living with dementia without concern. Examples within the theme indicate that such abuses may already have occurred (Sabat, 2006; Sabat, 2008). Academically the scoping review has justified the critical humanist basis for the thesis, indicating that it would be morally wrong to ignore harmful discourse, which leads to social injustice.

The positioning by people living with dementia (the ideal position)

Although the disparity between people living with dementia's positioning and that of other groups establishes a need to challenge the latter, the positions provided by people living with dementia should not be accepted as desirable for people living with dementia. The positions provided by people living with dementia may also inhabit a malignant space as suggested by several of the sources. There is evidence that people living with dementia do not wish to be placed with other people living with dementia who are in a different stage of the illness (Nowell, Thornton & Simpson, 2011). This may be a protective action as the person living with dementia does not want to see an exacerbated form of their own symptoms but this may contribute to the malignant positioning of people living with dementia in later stages of disease. It is not unreasonable to assume that people living with dementia may engage in malignant positioning themselves as people living with dementia have acknowledged that they have engaged in this form of positioning prior to their own diagnosis (Sabat, 2003). The *not like other people living with dementia* subtheme also alludes to people living with dementia wanting to be separated from behaviour they consider undesirable. It could be argued that positions indicate a desirable position for people living with dementia as they do not represent a malignant position for themselves. However, they are based on the continued presence of negative positioning for other people living with dementia.

Many people living with dementia do not wish to share their diagnosis outside of their close social circle (Langdon, Eagle & Warner, 2007) which could be related to malignant positioning by others. This is particularly pertinent when the person living with dementia has accepted that there may be very little that they can do to reposition themselves when provided with a negative position by somebody else (Sabat, 2003).

There was little evidence of people living with dementia defining desirable positions. Although preferable verbal positions could be alluded to through the review there was only one defined preferable position throughout the 755 results. It was observed that when people living with dementia were positioned as ‘incompetent’ their concordance with formal care would decline but when positioned as ‘independent’, they would give full co-operation to their formal caregivers (Snyder, 2005). This example clearly defines ‘independent’ as a preferable position for the person living with dementia in that particular study. There is also a clear perlocutionary effect attributed to both forms of positioning. The negative or ‘incompetent’ position results in the perlocutionary force of the person living with dementia becoming resistive to formal care. Depending on the caregivers understanding or reaction to this resistive behaviour, further negative perlocutionary forces may be experienced by the person living with dementia (e.g. medication prescribed as a mechanism to calm the person during formal care). The positive or ‘independent’ position results in the perlocutionary effect of the person living with dementia engaging with formal care thus resulting in their physical care needs being met.

The absence of literature concerning desirable positions for people living with dementia indicates a significant research gap.

Justifications

The scoping review has provided the following justifications for the thesis.

- The variation in verbal positions within the same domains between people living with dementia and other groups suggests that current verbal positions provided by others may be undesirable to people living with dementia. Negative positioning must be challenged.
- The current literature provided enough examples of verbal positions to create a five domain model. However, positions were taken from 71 different sources resulting in demographical data absences. Further research is required regarding the verbal positioning of the three groups (family, healthcare workers and lay people) within more clearly defined social and demographical data.
- The lack of defined desirable positions for people living with dementia in the literature justifies the requirement to engage with people living with dementia regarding this data.
- Desirable positions may have shared elements but will also be individual to each person. This hypothesis must be tested with people living with dementia.
- People living with dementia are aware of the negative positions used by other groups. Although this awareness is evident throughout the literature timeline, the positioning by others remains inconsistent with that of people living with dementia. This outcome justifies using a positive change methodology in the thesis.
- Negative verbal positions can result in perlocutionary forces that have a malignant and even, abusive outcome for people living with dementia. The need to identify how people living with dementia want to be positioned and to challenge others who may

position people living with dementia negatively may result in better health and social outcomes for people living with dementia

3.6 Summary

The first part of this chapter described the practical execution of a scoping review to explore how people living with dementia are positioned and how this group have suggested they would prefer to be positioned. The challenges of conducting a scoping review with a vast breadth of results was considered prior to a discussion of findings, framed by five domains, which had been developed through a thematic analysis. A synthesis of the findings relating to the inquiries of interest was presented and the chapter was concluded with a series of justifications for the empirical inquiry in this thesis.

The scoping review illustrated that the positioning of people living with dementia differs between social groups although the most significant differences observed occur between the positioning by people living with dementia and other groups. This disparity supports the proposition that people living with dementia are currently experiencing verbal positioning by other members of society, which they would consider unsupportive or malignant. The review also identified that literature detailing the positioning of people living with dementia by lay people is limited and there have been no serious research endeavours to understand what people living with dementia would consider to be ideal positioning.

Chapter 4

Findings: Discovery, Dream and Design - People living with dementia are empowered to identify the requirements for positive verbal positioning using the Discovery, Dream and Design phases of Appreciative Inquiry.

4.0 Introduction

This chapter will report on the first conceptual finding. This finding is directly related to the outcomes of the Discovery, Dream and Design phases of AI and the involvement of people living with dementia in the process. The research questions for this thesis as presented in chapter 1 were:

- Can AI support people living with dementia to define a lived experience of ideal verbal positioning by others?
- Can the outcomes of an AI cycle with people living with dementia influence the verbal positioning of other groups in society?
- What factors influence the verbal positioning of people living with dementia by members of society aware of the AI outcome?

From the data analysis completed during this thesis, four key conceptual findings are visible. As basic findings, these can be described as:

1. People living with dementia are empowered to identify the requirements for positive verbal positioning using the Discovery, Dream and Design phases of AI.
2. Four positioning themes as a framework to assess how people living with dementia experience verbal positioning by others.
3. Verbal positions that are directly influenced by the outcomes of AI.
4. Five thematic positioning identities as facilitators and barriers to positive verbal positioning as defined by AI.

The description of finding one will begin by providing the shared narratives of people living with dementia in the Discovery phase of AI and explore the external (those dependent on others) and the internal (those defined by positioning of the self) requirements of positive verbal positioning as defined by people living with dementia. A discussion of the Dream phase through six themes defined by people living with dementia is followed by an analysis of how people living with dementia were able to reflect on the first two phases of AI to inform the third, Design, leading to the creation of a short film to inform others about their ideal verbal positions.

4.1 Sample

Four people living with dementia engaged with the first three AI phases:

Pauline was a 64 year old female with a diagnosis of mixed type dementia (Alzheimer's and vascular dementia). Colin was a 64 year old male with a diagnosis of Alzheimer's type dementia. Gavin was a 56 year old male with a diagnosis of frontotemporal dementia. Sue was a 60 year old female with vascular dementia.

The sample size of four people living with dementia met the requirements documented in the ethical approval process. Although AI as a methodology is fundamentally unlimited in regards to the number of participants potentially involved, the focus on the narratives of the people living with dementia in this study resulted in the necessity of a smaller sample size. The exploration of people living with dementia's personal narratives through the format of AI is concordant with the proposal that smaller sample sizes should be used depending on the research paradigm and the context of the study (Boddy, 2016). As the thesis is located within the qualitative paradigm it cannot be justifiably dismissed due to its smaller sample size (Vasileiou, Barnett, Thorpe, & Young, 2018) as the purpose of qualitative inquiry is to induce and explore emergent, in-depth understandings (Dworkin, 2012) rather than generalise findings to mass populations. The in-depth exploration of the four people living with dementia's shared narratives demanded a qualitative approach and a sample size that permitted a substantial level of analysis. Inquiries involving narratives should not be conducted with larger sample sizes (Butina, 2015) as this will dilute the extent of any analysis.

4.2 Discovery

The four people living with dementia shared their individual narratives based on the Discovery question in pairs. The people living with dementia then shared their discussions with the group as a whole.

Pauline's Discovery narrative

Pauline described a recent occasion when she was invited to stay with a friend. Pauline shared that she had retired from her job as a landscape gardener shortly after receiving her diagnosis five years ago but was pleased when her friend asked her to design a rockery for her garden whilst she was visiting. Although her friend had some ideas regarding what she would like in her garden, she told Pauline that she would dismiss her own ideas for Pauline's as she had the greater knowledge and experience in this area. Pauline stated that being asked to design the garden provided her with a sense of what her life had been like before she had received her diagnosis, that people trusted her in her area of expertise. Pauline also spoke about having no fear of making a mistake as the treatment by her friend made her feel comfortable and so, even if a mistake did happen, there would be no undesirable consequences. Secondly, to this part of the narrative, her friend then asked her to join her on a canoeing trip. Pauline accepted the invitation and spoke about how in both incidents her friend, despite Pauline's diagnosis, never made any assumptions about what she was no longer capable of doing. Pauline shared that the key point in both of these incidents was that she was asked if she would like to do something, rather than being told what to do or told that she was incapable of something without being given the opportunity to try.

On introduction of the Discovery question, Pauline stated that the question was quite difficult as she felt that stories regarding her negative experiences far outweighed the positives. She also stated that remembering positive experiences was difficult as negative incidents were more memorable due to the ill effects they would have on her morale. However, despite Pauline's initial misgivings she introduced her narrative to Colin immediately after separating into pairs.

On joining the group as a whole, Pauline successfully recalled her narrative and supported Colin to share his own narrative during periods when he struggled to recall what he had shared in their pair. Pauline's contributions became greater as the other members of the group shared their narratives, applying them to her own experiences and asking them directly for further information when she felt their narratives demanded it. Pauline was empowered by her own narrative to offer prompts to Sue when the latter was finding the identification of a positive narrative difficult.

Colin's Discovery narrative

Colin shared an incident that had recently occurred during a public event. Colin stated that he is very proud of his history serving in the Royal Air Force (RAF) and believes that the public should show respect and gratitude to all previous and current members of the country's armed forces. He recalled an armed service march in his local area and his desire to be included in the lines for the RAF. He felt that his wife might have been initially unsure whether he would be able to take part in the march based on his ability to recall his movements in the marching line. However, on the day of the march he recalled seeing his wife surprised and celebrating as he successfully recalled how to march in line. He had noticed that the crowd had previously been relatively quiet but now observed a surge in clapping and cheering, led by his wife who was prompting the celebrations of others in the audience. Colin shared that he felt that his diagnosis was unimportant as neither his wife nor the larger crowd regarded him as a person living with dementia, instead viewing him as a respected member of the armed forces. Colin stated that the need for respect was central to his narrative and believed that this was borne out of his history of being respected in the RAF but was now equally important outside of his role in the armed services. Colin shared his belief that unless he is treated with respect, as he was during this incident, he could not be treated in a manner that would be acceptable to him. He also felt that this incident was particularly powerful for him as the march provided him with a meaningful purpose related to his prior life in the RAF, a purpose that he did not feel was apparent since his dementia diagnosis.

Colin recalled his positive experience immediately upon hearing the Discovery question. Prior to being asked the question, Colin had mentioned his previous role in the RAF to the group and his continued interest in the armed forces. He was physically animated whilst recalling his narrative with Pauline and stood up to demonstrate marching in line whilst explaining the procedure.

On joining the larger group, Colin was less animated and appeared to have difficulty in recalling the narrative in the same depth as he had whilst sharing the story with Pauline. Pauline prompted Colin during periods when he admitted that he had forgotten what he had previously said whilst in the pair.

Gavin's Discovery narrative

Gavin described an experience that he linked to an ongoing occurrence, related to his current employment. Gavin shared his current employment with the group, as a ticket cashier at a local fairground, which was a role he had been involved with for several years. He felt that whilst working, in general, his dementia did not affect his performance and therefore reduced any negative impact regarding how co-employees treated him following his diagnosis. The incident he shared was a relatively recent episode when a new computerised ticketing system was introduced to the fairground. He had personally assumed that he could have difficulty in using the new system but was surprised to find that he adapted to the new system much faster than his colleagues without dementia did. His colleagues would then ask for his assistance to use the new system due to his expertise. When this happened, Gavin stated that he felt that even though everyone he works with is aware that he has dementia, they do not treat him any differently to other colleagues. Gavin felt that key elements of this narrative were the sense of being treated with the same level of respect as others who do not have a diagnosis and having the opportunity to show that he could still excel in areas of his employment when others, without dementia, struggled.

Gavin was initially pessimistic about discussing the positive experiences following his diagnosis but used the question to consider different aspects of his life, regarding his family, friendships and work to recognise the context of when positive experiences did occur. Whilst sharing his narrative, Gavin also started to introduce his thoughts on the factors that allowed the positive experience to happen displaying a consideration for the larger inquiry beyond the personal story.

Gavin successfully retold his narrative, on joining the larger group. When Sue identified her work-based experience as the source of her positive experience, Gavin also supported her by making complimentary comparisons with his own narrative.

Sue’s Discovery narrative

Sue shared an experience that occurred prior to her diagnosis of vascular dementia. She described working in a bakery during a time when the manager was promoted and left the site, which created a vacancy for a new manager. Sue stated that she had not considered becoming a manager and did not think about putting her name forward for the role. Despite showing no interest in the position, she was approached by the bakery owner who asked her if she would take on the role. The bakery owner told Sue that they were very impressed by the job she had been doing and wanted to offer the role to her as she was a person they respected and trusted. Although Sue was initially reluctant to accept the role, she did take the position and shared that eventually she enjoyed the experience and was good at it. Sue felt that this experience was important as other people had recognised what she could do and she had not shouted about her good work. It was also important to Sue that other people felt she had the capability to achieve something and what she had already achieved was also regarded with respect.

Sue found the identification of a positive narrative difficult. She stated that she could not identify an experience when she had been treated with respect following her diagnosis. She then shared her belief that there had never been a time when she had been treated or regarded in a manner that she would prefer since her dementia diagnosis. As the process of Discovery is concerned with focussing on experiences that are regarded as high points for the person (Cooperrider, Whitney & Stavros, 2008) it was inappropriate for Sue to consider experiences when she may have felt only mildly content with the position others granted her as a means to identify the positive core. As the Discovery aimed to understand the contributory factors that created positive positioning for this group of people living with dementia, Sue’s narrative needed to come from a time when she felt that this positive experience had occurred. Therefore, for Sue, the Discovery question was repositioned to allow her to consider experiences prior to her diagnosis. Despite this change to the Discovery question, Sue stated that it remained difficult for her to remember a situation when she felt treated with dignity and respect, even prior to her diagnosis. Sue shared that this was not something that she had previously thought about and did not believe that she had achieved enough in her life to be treated with dignity and respect. This comment resulted in the other members of the group disputing this assumption, voicing their belief that everybody should be entitled to being treated with dignity and respect. It was Pauline who suggested to Sue that she should consider her experiences in employment that led to Sue identifying and sharing her narrative.

Whilst sharing her narrative in the pair, Sue was hesitant and appeared to be wary of boasting about her achievements and the respect she was shown by her employer. On sharing the narrative with the larger group, Sue was less hesitant, responding to the other people living with dementia's narratives and sharing her own story more confidently. Although Sue's willingness to share her narrative increased during the Discovery phase, she also dampened her importance in the story, regularly suggesting that if she had not taken the new position they could have found someone else to do it as she was one of many people working in the bakery. When group members challenged her on this assumption, stating that the owners had chosen her due to their trust and her abilities, Sue agreed but restated her belief that she did not feel she was that important.

Contributory factors

From the narratives shared during Discovery it was possible to identify the factors that contributed to the four people living with dementia having experiences of being positively positioned in regards to respect and dignity. Discovery narratives are the key to understanding the factors, which allow good experiences to happen. The factors enable the inquiry to understand whether there are thematic similarities between the shared narratives, which may indicate the experiential importance of certain experiences that lead to a desired outcome. These factors have been described as 'life giving' (Cooperrider, Whitney & Stavros, 2008 p.115) as it is these experiences that require nourishment and growth if positive experiences are to become regular occurrences.

The factors identified from the Discovery narratives were:

Others realise I need to have a meaningful purpose in my life.

All four people living with dementia attributed their positive experience to other people recognising their need for activities that were significant and positively consequential. Colin's narrative reflected a purpose that was significantly meaningful for himself whilst the remaining participants identified experiences were the eventual purpose of their actions had desirable consequences for themselves and others. All of the narratives required the input of other people for the activity to occur.

No one assumed that we weren't capable.

In all four narratives the people living with dementia did not experience anyone telling them that they could not achieve their venture due to a lack of ability.

We were treated like we didn't have dementia.

In three of the narratives, the people living with dementia described the positive experience as being dependent on their dementia having no influence on the manner in which they were positioned. This factor was absent in Sue's narrative as the story was taken from a period in her life prior to her diagnosis of dementia. The factor was also absent in Sue's general narrative as she voiced that she had never been treated with dignity and respect since her diagnosis.

Our opinion mattered.

Three people living with dementia felt that during their experience that they had opinions, which allowed them to influence the positivity or negativity of the event. This factor was dependent on the people living with dementia believing that their own opinions were worthwhile (as opposed to being dependent on the opinions of others). This factor was absent in Sue's narrative as she expressed her belief that despite her positive experience, she remained unimportant.

We were with someone close to us.

This factor appeared in 50% of the narratives. Both Pauline and Colin felt that having their family or friends with them during the experience influenced their subsequent positive thoughts about the event. Both Gavin's and Sue's narratives lacked this factor, with both recognising the characters in their stories in different ways. For Gavin, the other people involved in his narrative were colleagues, possibly friends but not emotionally significant. Sue described the other people as colleagues rather than friends although she did not feel she could say how they personally felt about her.

Somebody told other people that I should be respected.

This factor appeared in all four narratives and relied on another person to recognise the people living with dementia's need for respect and instigate this respect in others. For Colin, this person was his wife who demanded other people showed their appreciation during the march of the armed forces. For Gavin and Sue, this person was a co-worker who recognised that their abilities should be respected by other workers. For Pauline, the person was her friend who Pauline suggested made her realise that she should respect herself. This respect positioned the people living with dementia as part of a larger group.

We wanted to be there.

All four participants described experiences when they were in situations that were not objectionable to them. For Pauline and Colin, the experience was based on social events that they had deliberately chosen to attend. For Gavin and Sue, the experience was based on paid employment but equally, they both felt that being there was psychologically beneficial.

If something goes wrong it wouldn't matter.

In three of the narratives the people living with dementia did not feel that they would be blamed if they did not achieve what they aspired to do. Pauline explicitly stated that if her garden design was not what her friend had wanted there would have been no negative repercussions. For Colin, if he had been unable to march successfully, he believed his wife would never undermine him. Although Gavin's experience was linked to his employment he felt that no blame would be attached to any mistakes he made on the new ticketing system as other staff regularly made mistakes without any disciplinary consequences. This factor was absent in Sue's narrative as there would have been negative repercussions for her if the bakery did not run successfully.

Others recognise your competence even when you don't.

Three people living with dementia included this factor in their narrative. Pauline's friend recognised her landscape gardening abilities even though she had not used these in some time. Other staff regularly approached Gavin for assistance with the new ticketing technology and Sue's positive experience was dependent on the bakery owner recognising her abilities. This factor wasn't present in Colin's narrative as he felt his wife was unsure about his ability to engage in the march until she experienced seeing him achieve this.

We were seen as people with authority on our subject.

This factor appeared in three narratives and was the result of the people living with dementia's own thoughts about their achievements. By successfully completing the tasks they were given or chosen the people living with dementia felt they had proven that they had significant expertise in their specialist area. This factor did not apply to Sue's narrative as she felt that other colleagues could have successfully achieved the same results as her.

There were other people around me who had the same respected status.

All of the narratives contained this factor, which suggested that positive experiences were dependent on the people living with dementia being with people who were treated similar to themselves, creating a sense of unity. The respect shown to all the armed force's marchers represented this factor for Colin. Co-workers supported this factor in Gavin and Sue's narratives whilst Pauline felt that she and her friend respected each other equally.

We were able to show our skills and abilities.

This factor appeared in all four narratives and concerned the people living with dementia believing that their abilities were worthy of demonstration and celebration. For Sue, who had belittled her own achievement, this factor was still present as she shared her perspective that once installed as the bakery manager she had succeeded in doing a good job.

The people know I've got dementia but it doesn't matter.

In three of the narratives, the people living with dementia described the event as being unaffected by their dementia even when other people involved were aware of the diagnosis. Sue's narrative lacked this factor as the experience occurred prior to her diagnosis. In Sue's general narrative she shared her belief that since her diagnosis, she had always been judged by others due to her dementia rather than her abilities and knowledge.

Other people needed us.

This factor was present in three of the narratives and occurred when the people living with dementia believed that their presence was important to other people. In Pauline and Gavin's narratives this occurred when their practical abilities benefited others. For Colin, by joining the march he became an active member of the RAF again and the celebration of this provided him with a sense of importance. This factor was absent from Sue's narrative who felt that her position could be filled by another employee, reducing her importance to others.

Someone remembered that we can do things that they can't.

This factor appeared in three narratives. It was present in narratives when other people recognised that the people living with dementia had abilities that were superior to their own or others. Pauline's friend recognised her landscape gardening abilities were greater than her own, Colin's wife and the crowd observed Colin engaging in a ceremony they could not contribute to and Gavin's colleagues regularly asked for his support with the new ticketing system. In Sue's narrative, although she felt others could do the role, the bakery owner had recognised her abilities surpassed her co-workers, and therefore this factor was present in her narrative.

It was somebody else who realised that I was capable of doing something and wanted me to do it.

In three of the narratives the person living with dementia's capabilities were recognised prior to the event occurring by another person who supported them to use their abilities. In Gavin and Sue's experience this was attached to having their work competence recognised and then being supported to use their skills. For Pauline, her friend recognised her competence in landscape gardening and then asked Pauline to apply her talent practically. This factor was absent in Colin's narrative as his wife did not realise that he was capable of successfully joining the march until she saw him achieve this, although the factor was partially present as she did support him to attend the event.

Table 3 summarises which contributory factors were present in each of the Discovery narratives.

Table 3: Discovery contributory factors

Contributory Factor	Pauline	Colin	Gavin	Sue
Others realise I need to have a meaningful purpose in my life.	✓	✓	✓	✓
No one assumed that we weren't capable.	✓	✓	✓	✓
We were treated like we didn't have dementia.	✓	✓	✓	X
Our opinion mattered.	✓	✓	✓	X
We were with someone close to us.	✓	✓	X	X
Somebody told other people that I should be respected.	✓	✓	✓	✓
We wanted to be there.	✓	✓	✓	✓
If something goes wrong it wouldn't matter.	✓	✓	✓	X
Others recognise your competence even when you don't.	✓	X	✓	✓
We were seen as people with authority on our subject.	✓	✓	✓	X
There were other people around me who had the same respected status.	✓	✓	✓	✓
We were able to show our skills and abilities.	✓	✓	✓	✓
The people know I've got dementia but it doesn't matter.	✓	✓	✓	X
Other people needed us.	✓	✓	✓	X
Someone remembered that we can do things that they can't.	✓	✓	✓	✓
It was somebody else who realised that I was capable of doing something and wanted me to do it.	✓	x	✓	✓

Requirements for positive positioning

From the contributory factors identified in the Discovery narratives it is possible to understand what requirements are necessary for the person living with dementia to experience positive verbal positioning. Thematically organising the requirements dominated by the other positioner and those dictated by the people living with dementia's emotional and practical context provides greater clarity regarding the positioning requirements of people living with dementia that could potentially be influenced by an AI outcome. Factors that rely on the 'other' are conceptually labelled 'external requirements'. Factors that are dependent on the person living with dementia are conceptually labelled 'internal requirements'.

External requirements

The factors identified as external requirements are detailed in Table 4. The requirements for verbalised positive positioning are dependent on the illocutionary intention of the speaker (when the speaker is not the person living with dementia). Statements created externally of the person living with dementia dictate the verbal position allocated to them, as perceived by others. As positions constantly fluctuate, statements are open to second order positioning by others (including people living with dementia) although the successful delivery for an external requirement remains only within the domain of the other speaker. The ability to apply an external requirement to a position is inaccessible to people living with dementia. Positions that meet the expectations of the external requirements are visible to the partners present during discourse as they are dependent on spoken locutionary statements.

The factor, *Someone remembered that we can do things that they can't* will be used as an exemplar of an external requirement. For the requirement to occur, the speaker must state that the person living with dementia is not only capable of achieving something but also that the person living with dementia can achieve this with greater success than the speaker. If the speaker does not divulge either of these components, the external requirement is not achieved. This example does not necessitate the practical display of the person living with dementia's capabilities to justify the occurrence of the position but is instead completely dependent on the speaker as positioner. Any narratives that support this requirement remain independent of the person living with dementia, relying on the speaker to recall and respect the person living with dementia's capabilities. The person living with dementia has the opportunity to influence other speakers to adopt this requirement whether through verbal self-positioning or through their practical actions although the external requirement can only be fully achieved if the speaker accepts that the person living with dementia has greater capabilities than themselves within the specific context.

Once this position has been stated, other conversational partners in the discourse have the opportunity to support this requirement or dispute it. The external requirements (listed in Table 4) can be achieved by all speakers except for the person living with dementia. In this exemplar, the person living with dementia may position themselves as more capable than a person without dementia but this does not mean that the external requirement is achieved. The requirement would only be achieved in this instance if a speaker, who is not the person living with dementia, supported the person living with dementia's position. The person living with dementia, similar to any person, is able to positively position themselves but can only be positively positioned by others, if the other speakers meet the external requirements for positive positioning.

Table 4: The external requirements for positive positioning

The external requirements for positive positioning
Others realise I need to have a meaningful purpose in my life.
No one assumed that we weren't capable.
We were treated like we didn't have dementia.
Somebody told other people that I should be respected.
If something goes wrong it wouldn't matter.
Others recognise your competence even when you don't.
There were other people around me who had the same respected status.
The people know I've got dementia but it doesn't matter.
Someone remembered that we can do things that they can't.
It was somebody else who realised that I was capable of doing something and wanted me to do it.

Internal requirements

The factors identified as internal requirements produced three conceptual themes:

- Emotional need
- Abilities used

- Empowered

The internal requirements and how they are thematically separated is demonstrated in Table 5. These requirements represent the factors that are necessary for the person living with dementia to believe that they are being positively positioned by a speaker and are dependent on the person living with dementia's internal thoughts or beliefs. Other speakers have the ability to impact on the person living with dementia's personal thoughts and beliefs but they are internal to the person living with dementia and therefore may remain unknown to others during discourse. There are contextual similarities between the external requirement exemplar *Someone remembered that we can do things that they can't* and the internal requirement *We were able to show our skills and abilities* as both are concerned with the capabilities of the person living with dementia. The latter example differs from the external requirement as it can only be achieved if the person living with dementia has a positive regard for their own capabilities and the motivation to practically divulge these capabilities openly. In comparison, the external requirement is dependent on the speaker's assumptions about the abilities of the person living with dementia. Both components of the internal requirement are located within the person living with dementia and are not dependent on the narratives of others.

Although discourse delivered by other speakers can result in positioning that may be intentionally positive or negative, the meaning of the narrative to the person living with dementia is filtered through their own internal self-positioning. If the person living with dementia has an inherently negative view of the self, they are less likely to achieve the internal requirements of positive positioning and may feel that they are negatively positioned by others when this was not the intention of the speaker. Equally, a person living with dementia who is internally positive may not recognise or accept that they are negatively or malignantly positioned by others if this position is in conflict with their personal view of themselves.

The thematic concepts related to the internal requirements (see Table 5) are described here.

Emotional need

If the people present in discourse or the place of discourse are viewed as preferable or comforting by the person living with dementia there is an increased likelihood that the internal requirements will be achieved. People living with dementia are more inclined to feel positively positioned when located in desirable locations or if they feel attached to the people around them.

Abilities used

People living with dementia are more likely to view other's verbal positioning of them as positive if the person living with dementia already holds positive views about their own abilities. If the person living with dementia is able to demonstrate their abilities to others, this will also increase the likelihood of the internal requirements being achieved.

Empowered

A person living with dementia who believes that their thoughts and ideas carry equal, or greater, weight than people without dementia is more likely to accept positive positioning by others. People living with dementia who recognise themselves as valuable and vital to the needs of other people will feel that they have retained authority and therefore have greater capacity to achieve the internal requirements.

Table 5: The internal requirements

The internal requirements		
Emotional need	Abilities used	Empowered
We wanted to be there.	We were able to show our skills and abilities.	Our opinion mattered.
We were with someone close to us.	We were seen as people with authority on our subject.	Other people needed us.

Reflecting upon the research questions for this thesis, the external requirements of positive positioning are related to the positions defined by others, rather than the person living with dementia. It is these requirements, rather than then internal requirements, which have the potential to be influenced in others.

Reflections on Discovery

The Discovery phase was successfully completed by the people living with dementia who were individually able to identify and share positive narratives regarding the discourse of choice. These narratives contained sufficient depth to identify shared contributory factors that had supported occurrences of desirable verbal positioning by others. Through further analysis of the contributory factors, the outcomes of the Discovery allowed for a thematic division of positive positioning requirements. These two themes described the factors as impetus for the provision of positive positioning by others (external requirements) and the person living with dementia's personal view of the positioning as positive (internal requirements). The internal requirements were also thematically separated into three sub-themes that defined the context of individual factors.

The practical delivery of the Discovery phase was initially regarded with scepticism by the people living with dementia. All four participants immediately voiced their concern that identifying positive stories was more difficult than recalling their many negative experiences but were aware that the process was appreciative. AI aspires to find the strategies that have previously worked to make a desirable outcome, so that they can be presented to others who can attempt to adopt the same strategies (Reed, 2007), which are identified through the positive stories shared during the Discovery phase. AI allows for adaptations and in the event that participants cannot identify positive narratives, negative data can be used to identify what they feel is currently missing from their ideal reality, allowing negative data to be revised into an affirmative insight (Cooperrider, Whitney & Stavros, 2008). The identification of positive stories was instigated through the supportive structure of the group. Colin quickly identified his narrative, which emancipated Pauline and Gavin from focussing on their negative experiences and identifying their own positive stories. Sue had greater difficulty in moving from negative to affirmative thinking but was supported by the other participants who used their own stories to support Sue’s narrative.

The pre-diagnosis context of Sue’s narrative did not impair the inquiry. The hope and empowerment that is central to the Discovery phase may not always be identified through experiences from the chosen context (Cooperrider, Whitney, & Stavros, 2008). Adapting the Discovery question allowed Sue to share her best experience of being positively positioned by others regardless of her dementia diagnosis. Limiting Sue to only sharing a story following her diagnosis would have restricted the affirmative dialogue and her discursive freedom, which would disempower the narrative and limit the potential openness of the inquiry.

The traditional model of problem solving and a deficit-based approach to change is radically different to the affirmative processes in AI and participants may initially struggle to adapt to this new way of thinking (Cooperrider & Whitney, 2005). This was evident in the Discovery undertaken with the people living with dementia but equally the phase was completed successfully, resulting in a process that was empowering for the participants and successfully generative to identify the requirements of positive verbal positioning of people living with dementia by others.

4.3 Dream

To encourage the discursive freedom required for the Dream phase, the author asked the participants if they would prefer to take notes during their discussions or if they would prefer the author did this and review the notes at the end of the phase. All four participants agreed that they would prefer the author to scribe the written account of the discussion. The written account was then shared with the group following the first stage of discussions and the group allocated what they had included in their Dream to themes that represented their vision of the ideal world.

Themes in the Dream phase

From the process of Dream, six conceptual themes were identified to signify how the verbal positioning of people living with dementia would be different in the ideal world.

- A change in understanding (about dementia and me).
- Acceptance.
- What I can do.
- Who I am.
- Language.
- Ourselves.

A change in understanding (about dementia and me)

Throughout the Dream dialogue, all four participants spoke of a desire to live in a world where people 'understood' dementia. They foresaw a world with people who understood dementia and therefore the experience of people living with dementia, resulting in positive changes to how people living with dementia are verbally positioned by others. The complimentary factors supporting the theme are displayed in Table 6. Colin explained how the ideal world would differ to the current reality stating that at present the general understanding of dementia is poor in the general public and therefore people make assumptions which lead to negative outcomes for people living with dementia. He felt that people currently see the experience of dementia as the same for every person living with dementia but in the ideal world this wouldn't occur as people would be educated and therefore understand that the dementia experience is different for everybody. All four participants felt that an ideal world would also be an educated world but did not feel that this education would be provided academically. In their ideal world, other people would listen to people living with dementia and this would be the educative mechanism to provide the understanding they wanted.

The group suggested that the devastating emotional impact of being blamed for situations when something has gone wrong (that would not have occurred prior to their dementia diagnosis) would no longer occur in the ideal world. Equally, the group felt that there was a clear method to practically apply this to reality, suggesting that if people understood dementia they would not even consider blaming the person living with dementia in these situations. This Dream factor can be directly aligned to the external requirement identified during the Discovery phase, *If something goes wrong it wouldn't matter.*

The Dream factor, *When I'm scared I am not told to 'get a grip* was also described by the group as a practically applicable recommendation for the ideal world but with a greater focus on the emotional experience of the person living with dementia. Sue felt that being told to 'get a grip' creates a position for the person living with dementia as being weak, lacking resilience and potentially a burden. In an understanding society, Sue said this would not happen in the ideal world.

Gavin used a work experience to illustrate the importance of understanding in the ideal world. He described working in the fairground whilst a woman and a young boy were queueing for ride tickets. He observed the boy was shouting and behaving in a threatening manner to the woman. Gavin admitted that when the pair reached the booth he was annoyed by the child's behaviour and was dismissive towards him. The woman explained to Gavin that the child had autism and the behaviour was part of his symptoms. Becoming fully aware of the situation, Gavin moved out of the booth and spoke to the woman and the boy at a pace they appreciated and suggested possible rides for them. Gavin felt that by understanding the boy's situation his originally negative perception of the child positively changed causing Gavin to treat the boy in a more understanding manner. In the ideal world, Gavin felt that this would happen for people living with dementia.

Table 6: Factors of 'A change in understanding (about dementia and me)'

A change in understanding (about dementia and me)
People understand that I may choose or choose not to do the same as others due to my symptoms without being made to feel like I'm letting people down.
People understand that I might need space when there is lots happening around me.
People understand that having dementia can be scary.
When I'm scared I am not told to 'get a grip'.
I can say that I can or cannot manage to so something without being made to feel stupid or worthless.
People understand that I have an illness and I am not doing things wrong on purpose.

Acceptance

The participants described an ideal world where they would continue living in society without being judged negatively by others because of their dementia. The factors included in this theme are displayed in Table 7. All four participants agreed other people would accept people living with dementia's beliefs and motivations without prejudgement. All suggested that the theme was dependent on the fulfilment of the *A change in understanding (about dementia and me)* theme which would allow acceptance to occur. They considered the *Acceptance* theme experientially different to the former theme, which they regarded as situational and part of the ongoing experience of living in the ideal world whilst *Acceptance* was expected to be immediate and continually present.

Conflict existed in the group regarding what acceptance would look like with Pauline, Colin and Sue all agreeing that an ideal world would mean that it would not be necessary to share their diagnosis of dementia to access the dignity and respect they would expect. Gavin disputed this version of the ideal world, suggesting that by not revealing their diagnosis, people living with dementia would remain hidden and more controversially for the other members of the group, could not expect to be treated with dignity and respect if they did not share their diagnosis with others. Gavin argued that if his behaviour appeared unusual to somebody else it would be natural for them to assume that he was behaving inappropriately, possibly under the influence of alcohol. By sharing his diagnosis he felt that people would be more likely to accept his behaviour and therefore, accept him. Gavin drew on the example of the woman and the boy in the fairground ticketing queue as an illustration of this happening, outside of the context of dementia. He recalled an example when he felt the situation was reversed in his experience whilst using the post office. During that experience, Gavin struggled to count the money he needed to pay for his items and he observed that the cashier appeared irritated. He removed a card from his wallet that explained he had dementia and showed it to the cashier. Gavin felt the cashier then accepted that he might struggle to count the money but gave him the time to do so, with no evidence of the previous irritation.

Gavin admitted that he felt strongly about revealing his diagnosis to others as he had regularly experienced other people disbelieving him when he had told them he had dementia. Pauline also shared an experience when she had walked into the wrong room whilst attending a conference and apologised to the people in the room, explaining that she was lost and had dementia. As she left the room, Pauline overheard a woman say that she was lying about having dementia.

The group discussed if they needed to define whether they needed to reveal their diagnosis or otherwise when dreaming about their ideal world as what they truly wanted to experience in this reality was receiving respect from others and not being excluded from society (rather than identify the mechanism that influences this). Colin suggested the difference between the present and ideal reality would be that people living with dementia would not notice a difference regarding how they are accepted compared to their pre-diagnosis life story, as the diagnosis would no longer have an influence on this experience.

Table 7: Factors of 'Acceptance'

Acceptance
I am treated with respect.
I am treated like everybody else, just like I used to be.
All People living with dementia are welcome everywhere.
I don't have to explain to people that I have dementia.
When I tell people my diagnosis they accept it and don't tell me that I 'look fine'.
People are made aware that I have dementia and therefore my actions or behaviour are not seen by others as foolish or people say I'm making a nuisance out of myself.

What I can do

The Discovery narratives were directly referred to by the participants in the factors that led to the *What I can do* theme. The factors included in this theme are displayed in Table 8. All four participants agreed that the ideal world would see a positional shift for people living with dementia with others acknowledging what they were still able to achieve rather than immediately positioning them regarding abilities that they had lost. They collectively concurred that this did not mean that others should ignore the abilities that people living with dementia have lost as they accepted that they all required support from other people for certain practical tasks and acknowledged that they would require more of this support in the future. Their current experiences, however, tended to find them positioned within a context of lost ability with others tending to ignore what they were still able to achieve. Pauline, Colin and Gavin suggested that the Discovery phase had allowed them to celebrate what they had recently achieved or continue to achieve which enhanced their positive view of themselves. They suggested it would not be enough for people in the ideal world to recognise that they retained many of their abilities but they would also need to recognise that they were also practically superior in their area of expertise compared to many people without dementia. This view of the ideal world was directly influenced by what they had experienced in their Discovery narratives, all three of the people living with dementia experiencing occasions when their skills were not only superior to other people present at the time but also acknowledged as such.

Sue agreed that the ideal world should include celebration when a person living with dementia is able to excel at a task because they are an acknowledged expert in that situation but did not want every practical achievement celebrated. She described experiences when she had completed basic tasks, in which she had no impairment but the reactions of others suggested she had performed a miracle. Such incidents made her feel worthless and made her feel less confident when attempting tasks believing that the people with her are expecting her to fail. Pauline suggested this was similar to being treated like children. In the ideal world they felt that people living with dementia when completing everyday tasks shouldn't be immediately expected to fail but neither should there be an overly gratuitous celebration in the event they succeeded.

All four participants acknowledged that the ideal world was complicated, with people expected to celebrate some abilities and quietly accept others. However, as this vision was an ideal they agreed that all these factors should remain within the theme.

Table 8: Factors of 'What I can do'

What I can do
People recognise what I can still do without me having to shout about it.
When I do something well, people don't make a big fuss about it and make me feel like a child.
No one tells me that I can't do something.
My skills and abilities are still recognised.
I am allowed to do what I want to do.
My judgement is trusted (within my expertise).
I am trusted.
I am asked if I want to try new things. It is not presumed that I can't do them or just won't want to.

Who I am

The Dream as envisioned by the group was considered an ideal world for all people living with dementia but with the recognition of people living with dementia as individuals an absolute necessity. All of the participants agreed that people living with dementia should be treated as individuals but felt that this statement was too simplistic. The factors that created the *Who I am* theme are displayed in Table 9. All participants agreeing that other people would have received education about the different types of dementia. Gavin argued that in the ideal world people would know that although his dementia does not define who he is, it is now part of him and influences his thoughts and actions. Colin supported the ideal that the general public would be educated about the different types of dementia but would also recognise and respect the person they were. He suggested that in the current reality, the positioning of people living with dementia is influenced by the speaker's previous experiences with people living with dementia they know or have known in their own lives. Colin felt that the currently available awareness education, particularly the Alzheimer's Society's Dementia Friends, could be a mechanism to create this reality and suggested that in the ideal world, everybody would be a Dementia Friend. Sue countered this argument, suggesting that in her experience, attending one awareness session did not result in people automatically being friendlier to people living with dementia. Although the mechanism could not be agreed on, all four participants envisioned an ideal world where people would appreciate the various forms of dementia and how this might affect the person living with dementia, without ever positioning the dementia above the person.

Colin strongly suggested that in the idea world, people living with dementia are respected for who they were. Drawing on his Discovery narrative Colin stated that his previous history in the armed forces was a vital part of his identity that would be regarded with respect in the ideal world. All four discussed the need to respect the past of the person living with dementia but also demanded that people living with dementia would continue to be treated with respect, regardless of the severity of their symptoms. Pauline added that it would not matter whether someone was regarded as a high achiever or not prior to their diagnosis of dementia, they would be treated with respect throughout their life.

Table 9: Factors of 'Who I am'

Who I am
People recognise that different types of dementia means different symptoms but that we are all different people.
We are not instantly all seen as an old person in a nursing home.
My past is respected.
I am respected.

Language

All participants agreed that the ideal world as a whole was based around the language that would be used about, and with, people living with dementia, but that it was also necessary to identify certain aspects of direct language use that they would wanted to alter in their current reality. The complimentary factors for this theme are displayed in Table 10. All participants felt that a change in language did not always mean a change in the speaker's attitude towards people living with dementia. Pauline used her experience of visiting a hospital when she observed that the language used by health workers met the requirements of the dementia friendly guidance with the staff using the term people living with dementia instead of dementia sufferer. However, when the staff spoke to her she felt that she was treated like a child or someone lacking intelligence. All four participants agreed that language guidance was helpful and had led to some improvements in the current reality but in the ideal world, the intention behind the language used would also be positive.

Pauline described language that was childlike as a source of irritation, which was often delivered by well-meaning individuals. When talking to friends about activities she had been involved in, Pauline often experienced a reaction she considered condescending with friends suggesting 'oh, haven't you done well' or more problematically, 'awwh, bless'. All of the participants agreed that the role of the language used in the ideal world would be to treat people living with dementia as adults, not as children.

Gavin described an aspect of language, strongly linked to his concerns in the *Acceptance* theme, as a source of irritation. When describing his symptoms to others he had experienced people without dementia saying they had the same issues. When describing memory difficulties to a friend, they replied 'well I forget things as well'. Gavin felt that the intention was to normalise his symptoms but for him, the symptoms were belittled and therefore, so were his difficulties. All four participants agreed that prior to their dementia diagnosis they could occasionally forget things but this was completely different to having a neurological condition that was causing this to happen daily. In the ideal world, people would not belittle the symptoms of people living with dementia in this manner.

Sue described language that she found extremely hurtful, stating that on several occasions she had been described as 'stupid'. She admitted that dementia had damaged her confidence but when people used this type of language it could be more devastating than the dementia itself. The other participants did not feel that they had experienced this language to the same degree of severity as Sue but all agreed that this type of language would be entirely absent in their ideal world vision.

Table 10: Factors of ‘Language’

Language
I am not called ‘miserable’ because I don’t want to do something.
No one calls me ‘silly’ or ‘stupid’ because I don’t understand something, don’t agree with them or I’m upset.
I am not pitied and spoken to like a child – ‘Awwh bless’.
I am treated as an adult.
People don’t belittle what I am living with by say ‘I do that as well’ when I explain my symptoms to them.

Ourselves

All four participants agreed that rather than attempting to understand many isolated ideas, allocating individual factors to overarching themes had made the vision of the ideal world clearer. Following this allocation, the four people living with dementia stated that they were happy with their definition of how people living with dementia would be positioned within this envisioned reality. Two factors that were identified during the Dream discourse were not considered applicable to the five themes identified. Pauline suggested that a new theme was required that went beyond the original proposition for the ideal world. She stated that the two remaining factors were not applicable to the identified themes as they were not about positioning by other people but actually changes in people living with dementia that would also happen in the ideal reality. They all agreed that neither of the factors required a change in other people but recognised that if these changes did not occur in people living with dementia, it would not be an ideal world and therefore they had to be included. The factors allocated to this theme are displayed in Table 11.

Pauline stated that although the discussions during the inquiry had been about issues that all four of them felt strongly about and therefore very serious, they needed to be able to laugh and not take themselves too seriously. Gavin agreed, stating that if they could not laugh at themselves they would become depressed. All participants agreed that receiving their diagnosis of dementia was one of the most devastating moments of their lives but they had been amused occasionally by incidents caused by their symptoms since that time. In the ideal world, no one else would laugh at these situations but people living with dementia would feel free to react with laughter, individually and together.

Reflecting on the ideal world, the four people living with dementia recognised that the positioning by others they considered negative was often built on assumptions regarding their abilities and personality. They suggested that they were also guilty of this negative positioning, often seeing the worst in themselves particularly when they struggled to achieve something that they had previously been able to do. They shared the belief that it was experientially worse for people living with dementia when another person negatively positioned them but agreed that if the person living with dementia continued to position themselves negatively, it would not be possible for them to feel good about themselves even if the other speaker was attempting positive positioning. In the ideal world, people living with dementia no longer view themselves through this negative lens and have a predisposition for positive self-positioning.

The *Ourselves* theme shares the ethos of the internal requirements identified through the Discovery phase. They are both dependent on the person living with dementia's view of the self, which may be shaped by the views of, or positioning by others or independent from these external influences.

Table 11: Factors of 'Ourselves'

Ourselves
We are no longer our own worst judges.
We can laugh at ourselves but no one else laughs at us.

Reflections on Dream

The four people living with dementia were able to successfully undertake the Dream phase of AI and propose an ideal world scenario in regards to the verbal positioning of people living with dementia. Through discourse they were able to identify 25 factors they considered as vital components of their dream reality. On reviewing these factors the people living with dementia were able to identify five conceptual themes that constituted the difference between their ideal world and the current reality in regards to the positioning of people living with dementia by other members of society. One conceptual theme was created to address the differences in people living with dementia's self-positioning between the current and ideal world.

All of the participants engaged with the practical completion of the Dream phase. Concerns that visions of the ideal world may go beyond the remit of the thesis (e.g. in the ideal world the person would not have dementia) were unfounded with the participants remaining focussed on the research question. The creation of conceptual themes to refine the dream scenario appeared to enhance the motivation of the group to envision a conceptual ideal world. Whilst the Discovery phase appeared to have empowered the group to recognise what positive positioning has and should look like, the Dream phase emancipated the participants to creatively express their desires, with demands becoming greater through the discursive support provided by each person living with dementia to the other members of the group.

Dream offers the opportunity for mutual discovery, rather than analysis (Cooperrider, Whitney & Stavros, 2008) with the focus placed on the vision of what should be rather than how we should get there. For the people living with dementia, discussions did occur to identify how change could happen in some circumstances (e.g. the use of education to understand dementia) but limiting these conversations would have denied the group's growing sense of power and social justice for people living with dementia. Equally, although many of the differences between the ideal and current reality were nurtured from experiences of negative positioning for the group, the Dream phase allowed a repositioning of these negative experiences to envision what an ideal reality would look like when the person living with dementia was positively positioned.

All of the group benefited from the discursive freedom that the Dream phase encourages although Sue's demeanour was noticeably different from the reluctant speaker at the commencement of Discovery. Sue started the AI with a scepticism about the process and was reluctant to speak. By sharing and listening to Discovery stories she recognised that positive positioning could occur but with a resigned acceptance that it did not occur frequently in her experience. In the Dream phase, Sue was empowered to speak freely, providing a greater presence in the group and spoke angrily about wanting the situation to change. When the phase had finished she spoke warmly about what she and the three other participants had achieved. During Discovery and Dream, Sue had moved from being a reluctant engager, to a resigned acceptance about negative positioning by others, to anger about the same positioning and finally pride, about envisioning a world where this negativity no longer existed.

Cooperrider and Whitney (2005) suggested that the Dream phase is similar to an artist who is inspired by the things worth valuing. For the people living with dementia, the phase provided sufficient inspiration to conceptually theme an ideal world in relation to the aims of this thesis. An unexpected but welcome outcome was the growing empowerment of the people living with dementia who took greater control of the process, supporting each other to speak freely about their desires and demands for social action. At the conclusion of the Dream phase, Pauline stated that she was excited to see what they would be doing in the next phase and the other participants agreed, suggesting a growing belief in the process of the AI methodology, which they had initially regarded with scepticism.

4.4 Design

Following the completion of the Dream phase, a typical AI turns its attention to creating a new reality, often through the identification of organisational principles and provocative propositions for participants and the organisation to deliver. A key question to this thesis is whether AI can be used by people living with dementia to influence a change in other people, outside of the participatory group. Therefore, the Design phase did not ask the participants to make propositions for themselves but instead empowered them to Design a mechanism to influence a change in others. During the ethical approval process for the study, the creation of a film had been identified as the mechanism of change, which had been agreed with the participants during the consent process, prior to beginning the AI. The content and direction of the film was not predetermined and its design was solely in the control of the research group.

The group were not asked to complete the film on the same day as the Discovery and Dream phases with a separate day already allocated for the Design phase. Gavin stated that he would prefer to film his own material on the separate day to provide him with the time to consider what he wanted to include. The remaining three participants decided to complete the film on the same day as the other phases, stating that they were currently motivated to carry on with the process and both Colin and Sue raised concerns that leaving the filming could affect their recall, regarding what they wanted to include. Therefore, three people living with dementia completed the filming and their involvement in the AI process in one day. Gavin completed the filming and the process over two days. The data collection and film production process of Design is detailed in section 2.4.2.

Bridging Discovery and Dream to Design

All four participants spoke positively about their Discovery narratives and their pride about envisioning an ideal world. Pauline suggested that the ideal world was the key message required for the film, as this would let other people know how to position people living with dementia positively. Gavin argued that without the initial context of the Discovery narratives the film would lack a basis in reality, which could mean that people might dismiss what they had to say as a fantasy. He expressed a reluctance for the language of AI to be used in the film, suggesting that the word ‘dream’ could potentially strengthen negative perceptions of people living with dementia as ‘not living in the real world’.

The four people living with dementia agreed that the film would include the two phases they had previously completed during the AI. Gavin suggested a ‘talking heads’ approach with each of them facing the camera, one at a time to relay their stories and then providing indicators about how they wanted to be treated in the future. He also suggested that each of them should choose which Dream factors they wanted to discuss, particularly as there had been differing opinions regarding diagnosis sharing. The group requested that the author wrote the factors in large text on paper once they had been chosen by each participant. These papers were used as prompts for the people living with dementia whilst filming. None of the participants wanted to create a full script for the film and requested that the camera should film them continuously and if there were any incidents when they lost their words or made a mistake, this should be edited out of the finished film afterwards.

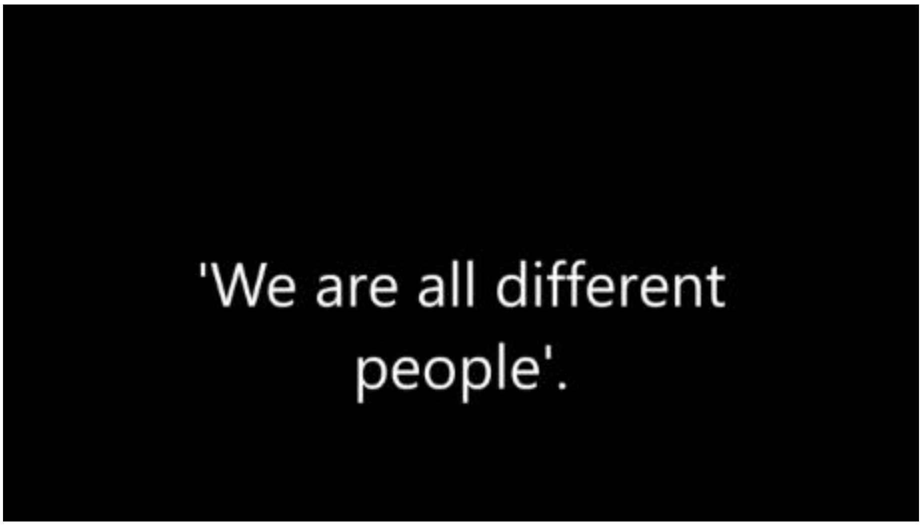
Pauline was the first participant to be recorded, followed by Colin and Sue. Gavin watched the other participants creating the film on the day but abided by his previous decision to be recorded on a separate day. Gavin's recording was completed on a separate day during the same week as the earlier AI phases.

The participants wanted to include a verbal statement before each of their sections in the film and asked the researcher to identify a quote from their individual narratives. The quotes were included in the film and displayed as presented in Figures 16 – 19.

Figure 16: Pauline's introductory quote (Quote from 11.09.2018)

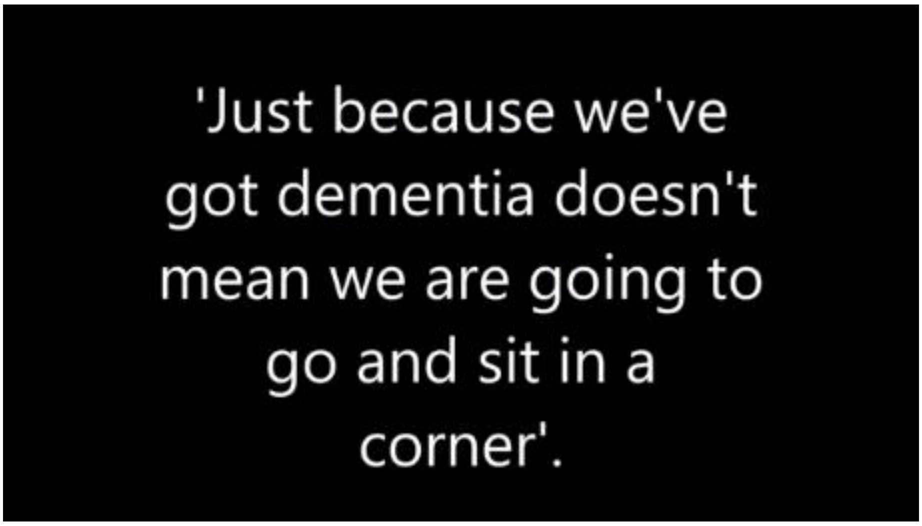
'Don't treat us like children'.

Figure 17: Colin’s introductory quote (Quote from 11.09.2018)



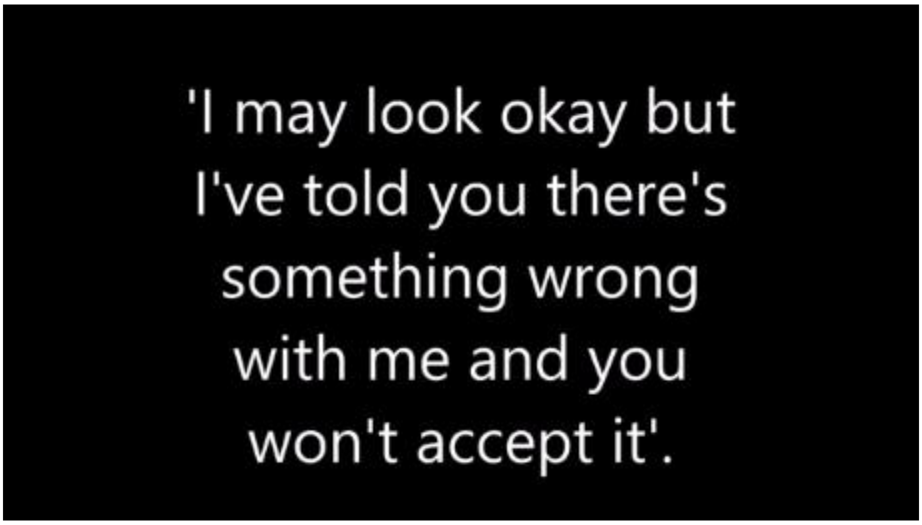
'We are all different people'.

Figure 18: Sue’s introductory quote (Quote from 11.09.2018)



'Just because we've got dementia doesn't mean we are going to go and sit in a corner'.

Figure 19: Gavin’s introductory quote (Quote from 14.09.2018)



'I may look okay but I've told you there's something wrong with me and you won't accept it'.

Reflections on Design

All four participants immediately saw the earlier AI phases as the mechanisms that lead to Design. They considered the empowerment they had gained from completing Discovery and Dream, the stimulus for inciting changes in others. From the authors perspective, introducing an open Design (under the restrictions of the short film concept) was potentially a difficult component of the AI process, due to its demands on the participants creative and organisational abilities. The Design itself, however, was agreed between the four participants after a short discussion with a clear conceptual intent as the people living with dementia reflected that as the AI process altered their own thinking, the content could also alter the thinking of others.

A second day for filming had been included during the research design phase to counter any fatigue that may occur following the completion of Discovery and Dream. As both phases demand continual involvement of the participants, it was considered an appropriate measure to complete the Design phase on a separate date. Colin raised concerns that his memory may impair his ability to recall what he wanted to include if he waited for another day to record his role in the film. Similar to the group discussion in Discovery, Colin did find retelling his narrative more difficult than he had during the pairs discussion in Discovery. Colin was able to relay his narrative but also started to speak about his time in the RAF to a much greater extent than when he had previously told his story. Colin stated that he was happy for any material not related to the research question to be edited from the final version. Pauline requested that the camera was turned off whilst she was being filmed as she had lost the focus of her sentence. When she was reminded that it would be possible to edit the video afterwards, Pauline was happy to continue and asked for the camera to continuously film whilst she talked and asked for it to be later edited. Mirroring her AI experience, Sue was quiet at the start of filming but gained confidence to strongly demand action as she discussed the ideal world. Gavin was able to successfully recall his narrative during his recording, later in the same week, stating that he found the cue cards for the Dream factors particularly useful. With all four participants consent, the film was edited into a short film, with a length of seventeen minutes and five seconds, which the participants named, ‘Four people, four experiences’.

Although this Design was not typical of the AI cycle, the outcome remained in the prerequisites of the phase as the people living with dementia integrated the best of the past and possible future to create an innovative product with an aim to influence positive social action in others. The use of Discovery and Dream to create this final product illustrates that all three phases of AI were required for this outcome to be achieved. Ignoring either of these earlier phases would have considerably altered the product and the feelings of empowerment experienced by the participants may not have been achieved. Crucially, the participants felt able to share their demands for social change, supporting the critical humanist stance of the thesis.

All four participants stated that they enjoyed completing the three AI phases. Sue spoke to the author directly to provide feedback about the process that was directly related to the *Language* theme in Dream:

> *'I was scared that I would be made to look stupid. I want to thank you because this has not made me feel like this at all. Thank you, thank you for not making me feel stupid.'* (Sue)

4.5 Summary

The thesis asks 'can AI support people living with dementia to define a lived experience of ideal verbal positioning by others?'. The Discovery phase provided the experiential context for the participants to define the experience of 'ideal verbal positioning' in Dream. AI was an emancipatory experience for the people living with dementia as it freed them from their initially sceptical and negative view of change and provided the freedom that allowed them to creatively envision how things should be and design a product to demand how they could be. For the aims of this thesis, the successful completion of the AI phases allowed the research to progress to the next stage. The supportive, empowering and emancipatory elements of the process, however, are equally important when considering how the methodology can be potentially used with people living with dementia, and other groups considered marginalised in society, in the future.

The factors identified in Discovery allowed for a thematic analysis to identify the external and internal requirements for positive positioning. The Dream phase empowered the people living with dementia to co-construct an ideal reality were people living with dementia are positively positioned during all discourse. This co-construction was used by the people living with dementia to identify conceptual themes to describe how the ideal world was different to the current reality. The two earlier phases were used during Design to successfully inform the creation of a short film. This product was designed as the mechanism to initiate positive change in the verbal positioning of people living with dementia by other members of society. As a process to create a product related to verbal positioning, the use of AI was a success. Beyond the practical outcomes, the AI process empowered the people living with dementia to demand social justice and action for themselves and other people living with dementia.

Chapter 5

Findings: Discovery, Dream and Design - Four positioning themes as a framework to assess how people living with dementia experience verbal positioning by others.

5.0 Introduction

This chapter continues to discuss the outcomes of the Discovery, Dream and Design phases of AI, reporting on the second conceptual finding:

2. Four positioning themes as a framework to assess how people living with dementia experience verbal positioning by others.

Finding two is concerned with four themes that emerged from the analysis of the AI outcomes and how these themes informed the Balancing Framework as a novel approach to assess the achievement or denial of positive verbal positions described by people living with dementia during AI. The active use of the Balancing Framework in positioning theory analysis is illustrated using examples from the AI process.

5.1 Four positioning themes

From the external requirements identified through Discovery it was possible to identify four positioning theory (Davies & Harré, 1990) themes in the context of the people living with dementia's experience.

- Belonging
- Able
- Supported
- Dementia Unseen

For the four conceptual positioning themes, the ten external requirements were selected as reporting the lived experience of positive verbal positioning for people living with dementia. The ten external requirements were thematically refined to eight requirements using Braun and Clarke's (2006) framework. The external requirements were thematically separated to articulate the conceptual themes that illustrated the contexts for significant positioning outcomes from the viewpoint of people living with dementia. These four themes were mapped to the twenty-nine factors relating to ideal positioning by other speakers identified during Dream to analyse their validity as conceptual themes within the ideal, as well as the current, reality. Within each of the four themes, two sub-themes were articulated. The narratives shared through the short film were used to articulate how the conceptual themes and sub-themes were addressed by people living with dementia's through Design. From the thematic analysis (Braun & Clarke, 2006), the themes and sub-themes are displayed in Table 12.

Table 12: Themes and sub-themes of positive positioning

Theme	Belonging	Able	Supported	Dementia Unseen
Sub-themes	Respect	Capable	Purpose	Doesn't matter
	No blame	Superior	Encourage	No dementia

5.2 Belonging

This theme synthesises and articulates the external requirements that emphasise a shared understanding between people living with dementia and the speaker. The understanding described through the external requirements represents the illocutionary forces that have the potential to increase the positivity of the perlocutionary outcome for people living with dementia. For people living with dementia, a positive perlocutionary outcome is not the speaker's understanding but the actions that are derived from that understanding, which should contribute to people living with dementia feeling that they have an equal social belonging to other speakers that is not jeopardised by accusatory language or actions by others. Three external requirements reside within the *Belonging* theme. Two of these external requirements, *There were other people around me who had the same respected status* and *Somebody told other people that I should be respected* are amalgamated to create the sub-theme of *Respect.* The remaining external requirement applied to the theme, *If something goes wrong it wouldn't matter,* is articulated in the sub-theme *No blame*. Through mapping the theme and sub-themes, the conceptual themes from Dream, *A change in understanding (about dementia and me)*, *Acceptance* and *Who I Am* are representative of positive positioning within the *Belonging* theme.

Respect

Colin applied the experience he had previously shared in Discovery to illustrate the continued need for respect. The narrative encapsulates both external requirements applicable to the sub-theme, with Colin sharing a respected status with the other marchers whilst his wife acted as an advocate for him (and the other marchers) to demand that others demonstrate their respect:

> *When we first started the marching, everybody out there was watching the parade and they said nothing, they were just dumb. My wife turned and said 'hang on, these people have*

> *fought in the war, right, if these people hadn't done what they've done, right, we'd be speaking Russian'. She said 'show respect' and (wife's name) made sure that everybody clapped all the way to the end…that's how it should be.* (Colin)

All the people living with dementia drew on experiences of negative positioning to create affirmative directions that would allow them to be positioned as respected. Pauline considered the misconception that people living with dementia regress to become children again to share how she would expect to be treated. Pauline drew directly from a Dream factor in the *Language* theme to illustrate her expectations of others:

> *Don't treat us like children. Don't change your tone of voice when you speak to us. When you hear we have a diagnosis of dementia, please don't alter your voice and treat us with pity. Don't say 'awwh, bless you'. Just treat us the same. We don't want your pity, so please, just treat us with respect.* (Pauline)

The demand for other people to broaden their understanding of the lived experience of dementia is applicable to all the positioning themes but was recognised as central to the provision of respect. For Pauline, respect was not about formally recognising a person through their achievements, which may have been implied through Colin's narrative, but could be the act of respecting the emotional reality of the person living with dementia through a patient approach:

> *To understand if you are getting anxious or have challenges to sort of, be patient and understanding of that. But they should be like that with anybody without you having to say you've got dementia. Although I don't mind telling anybody. Some people don't like to say and you shouldn't have to.* (Pauline)

Gavin considered respect as a mechanism for other people to believe what the person living with dementia shares with them. He related this to experiences when acquaintances had doubted his suggesting a lack of respect towards him as a person living with dementia compared to people with physically apparent diseases:

> *When I say I've got FTD…they don't want to accept that's what the problem is. I'll say to them I've got FTD and they say 'you look okay to me'. Well, I'm not okay. I've told you I'm not okay. You know I'm not okay. I feel that if I had cancer, they wouldn't question that I had cancer…why would you question that I have a dementia?...I've told you there's something wrong with me and you won't accept it…because it's not on show.* (Gavin)

Gavin expanded on this narrative, stating that people had outright dismissed his disclosure of dementia. Respect in this narrative was informed by the *Acceptance* theme from Dream. Gavin perceived respect as personally applicable to the person living with dementia but also necessary for the diagnosis, with dementia granted the same respect as other life altering diagnoses:

> *'You look fine, you look okay to me. There's nothing wrong with you' and I've had people say that to me. You wouldn't say to anyone you've got dementia if you didn't have it. You wouldn't*

> *say to anybody you had cancer if you didn't have it but they accept the cancer thing without question. You'd only have to tell someone once you had cancer and every time someone sees me, they still say to me 'you look fine, you look okay'.* (Gavin)

Gavin applied the absence of respect he had recognised for the diagnosis to the symptoms of dementia, suggesting that it was disrespectful for other people to suggest that they could realistically empathise with living with memory loss. He suggested that people living with dementia's symptoms should be treated with the same respect as the symptoms of other diseases rather being used comparatively with 'healthy' individuals:

> *I've got problems with my memory – 'oh yes, I can't remember people's names and I can't do this and I can't do that'. They want to compare what they can't remember to what you can't remember and they just wouldn't do that with any other disease.* (Gavin)

Whilst Gavin used these experiences to illustrate areas where people living with dementia could be disrespected and therefore could potentially change, Pauline provided direct guidance for speakers:

> *When you say no, take no for an answer.* (Pauline)

The people living with dementia addressed the sub-theme of *Respect* by diversely including the formal respect for current and past achievements whilst including an ongoing demand that the person living with dementia is listened to by others and what they have said is regarded with respect.

No blame

Pauline used the narrative she shared during Discovery to illustrate the value of trusting relationships without negative consequences. During the narrative Pauline acknowledged that her friend regarded the creation of a rockery as important and although she believed that Pauline was able to do this, resulting in the narrative supporting the *Able* theme, there were no implications of negative repercussions if Pauline had failed to achieve the task. The people living with dementia did not deny that their abilities had changed due to dementia but there was great value attached to the belief that a failure to achieve an ability should be accepted by the other person, rather than used as a mechanism to accuse the person living with dementia of malevolent actions:

> *She trusted that I'd know what I was doing and even if I hadn't known, if I'd got it wrong that would have been fine.* (Pauline)

Using this affirmative narrative, Pauline applied the principle to her negative experiences when she had felt blamed for her emotional distress. All the people living with dementia agreed that they have expressed their emotions more openly since their diagnosis but demanded that other people should not negatively judge them when this happens:

> *If you get upset or if you find something really challenging…remove yourself from a situation because you know it's going to bring on a bit of a meltdown…I'd like people to understand that.* (Pauline)

As these emotions are personal to the person living with dementia, Pauline described situations when other people often told her she was reacting inappropriately when she wanted to remove herself from situations she found challenging. Pauline demanded that other people accepted this emotional experience, rather than accusing her of overreacting, by acknowledging her reality whilst maintaining the opportunity for her involvement:

> *If I said I'm gonna go now or…I can't come to that, just to understand and say 'okay, that's fine, if you change your mind let us know'.* (Pauline)

Whilst the accusatory potential in Pauline's recommendations were acknowledged as conceivably delivered by people with no ill intent, Sue described accusations that she experienced as 'evil'. Although Sue had referred to other accusatory words she had experienced, it was the word 'stupid' which she felt was most damaging. Whilst 'stupid' in the context of dementia could potentially be the other person's reaction to the person living with dementia's deteriorating abilities, it also suggests that the person living with dementia may be in control of this deterioration. Sue stated that the symptoms of dementia did not make the person living with dementia 'stupid', as the person living with dementia could not overcome their symptoms through education. This was not regarded as a grey area with the demand that by blaming people living with dementia in this manner was abusive and maliciously intentioned:

> *If you're upset or you find it hard to work something out, or you've not understood what they've said and you ask them again, they'll come out with 'oh, you're being silly, I've told you that'. The other one is 'stupid', 'don't be stupid'. As I often say, I am far from stupid, it's just my memory gives up. I really do dislike that word. There's got to be another word that people can use that doesn't take people down with the word 'stupid'. There's got to be. Because that is so upsetting. It's an abusive word. Calling people 'stupid' and when they've got something wrong, they don't want to hear it.* (Sue)

By drawing on the themes in Dream directly connected to the *No blame* theme, the group illustrated how other speakers could overcome accusatory perceptions through a greater understanding of dementia and an acceptance of the person living with dementia's lived experience.

5.3 Able

This theme synthesises and articulates the external requirements that recognise the person living with dementia's continued abilities. Three external requirements reside within the *Able* theme. Two of these external requirements, *No one assumed that we weren't capable* and *Others recognise your competence even when you don't* are amalgamated to create the sub-theme of *Capable.* The sub-theme addresses positions that may be directly applied by speakers through assumptions or observations regarding the person living with dementia's ability. Perlocutionary effects of ideal positioning related to this theme encourage greater use of the person living with dementia's recognised abilities and have the potential to enhance the morale of people living with dementia. The remaining external requirement applied to the theme, *Someone remembered that we can do things that they can't* is articulated in the sub-theme *Superior*. This sub-theme illustrates speakers who recognise that the person living with dementia's capabilities are greater than their own, in the person living with dementia's field of expertise. Through mapping the theme and sub-themes, the conceptual theme from Dream, *What I can do is* representative of positive positioning within the *Able* theme.

Capable

Key to this sub-theme was the other speaker's recognition of the individual's abilities. Although Sue was unable to locate a narrative that described these experiences in the context of dementia, through her Discovery narrative she was able to share how this recognition had occurred prior to her diagnosis. Sue used the narrative to illustrate the importance of being able to use abilities to their fullest degree, admitting that she was initially unsure about accepting a managerial role whilst also recognising that in hindsight, the recognition of her ability did result in a positive experience:

> *Somebody suggested, me stand in for a manager on her day off. I wasn't too keen on the idea I must admit but I did and that lasted five, maybe six years if not more. I did enjoy it in the end, I must admit.* (Sue)

Pauline's narrative included a similar outcome using an experience, which occurred following her dementia diagnosis. By requesting Pauline to design a rockery, her friend recognised that she remained capable which Pauline acknowledged had an uplifting effect on her morale. Being positioned as capable resulted in Pauline feeling pride, not only in her acknowledged ability, but also in the trust that her friend had shown she had in these abilities. The speaker asked Pauline if she wanted to design the rockery but did not ask her if she felt capable of doing it. The speaker had already presumed that Pauline retained this capability, resulting in this positive positioning:

> *I was really proud that she'd put that trust in me…she trusted that I'd know what I was doing.* (Pauline)

The sub-theme *Capable* is illustrated in all four narratives that had been previously shared through Discovery. Although the people living with dementia make direct recommendations for other people in regards to their positioning of people living with dementia, in this theme the narratives imply the requirement to presume the potential capabilities of people living with dementia rather than assume incapability.

Superior

To achieve a positive position within the scope of the *Superior* theme it is absolutely necessary that the person living with dementia is accepted as *Capable.* Gavin described the practical application of a *Superior* position in his Discovery narrative. Although he admitted that he was surprised at the high level of functioning he displayed when using the new ticketing system, it was other people's reliance on his knowledge and skill that enhanced his experience:

> *So, when they come on the radio and ask for your advice on how, you know, how a sub-menu has to be fetched up or whatever it might be, it just makes you feel normal for a change. That they're coming to you for some advice.* (Gavin)

Gavin suggested that there was an expectation, which he admitted to sharing, that a person living with dementia is expected to be the person asking for assistance. He admitted that asking for help did not faze him but the expectation that he requires assistance in every situation could be demoralizing. In this situation, being the regarded as the expert and therefore *Superior* to his co-workers led to a preferable position:

> *They come to you for advice, so that's much better.* (Gavin)

Being regarded as an expert was a central aspect of Pauline's Discovery narrative. Her friend's request for her help had achieved the positive requirements related to the *Capable* theme but by acknowledging that she was made the request because she had recognised capabilities in Pauline that she did not personally have, strengthened the positivity of the position allocated to the person living with dementia. In this narrative, the superiority of the person living with dementia is evident, as Pauline is left to complete the job independently:

> *She said the real reason apart from wanting to see me was to, sort of use my expertise of when I, of a landscape gardener 'cause she wanted a rockery doing and she left me to design it and actually do all the work for it and at the end, she just left it all up to me, left me completely on my own to do it and when it was, when it was finished I had this real sense of achievement and I was really proud that she'd put that trust in me, to leave it up to my judgement. She trusted that I'd know what I was doing.* (Pauline)

Whilst Colin's wife would have initially positioned him as possibly incapable of marching prior to the event occurring, by successfully completing the march, Colin recognised a change in his wife's estimation of him as he had a skill that she did not share. This attitude change to positive *Superior* thinking resulted in his wife influencing others to adopt positive positions in the *Respect* theme:

> *When we were marching we came to a point where we stopped and we stopped in the military form, which is..t…t..stop and then we carried on. Step aside and then step easy, left, right and (wife's name) was looking over and she was gobsmacked at the military engineer that was still in there.* (Colin)

The group's narratives and demands informed an *Able* theme that requests other speakers to take a position of assumed capability, without denying the potential decline in the person's abilities due to the symptoms of the syndrome.

5.4 Supported

This theme synthesises and articulates the external requirements that recognise the person living with dementia's continued need for a meaningful existence and the expectation that other people will uphold this need. Two external requirements reside within the *Supported* theme. One of these external requirements, *Others realise I need to have a meaningful purpose in my life* informs the sub-theme of *Purpose.* The sub-theme is the direct recognition of the person living with dementia's requirement to continue living their life in a direction that has meaning to them and may have positive repercussions for themselves and others. The remaining external requirement applied to the theme, *It was somebody else who realised that I was capable of doing something and wanted me to do it* is articulated in the sub-theme *Encourage*. This sub-theme illustrates speakers who recognise the person living with dementia's need for meaningful purpose and enable them to achieve their desired outcome. Through mapping the theme and sub-themes, the conceptual themes from Dream, *Language* and *What I can do* are representative of positive positioning within the *Supported* theme.

Purpose

An overall recognition of the need for meaningful activity is the base requirement for the sub-theme and theme to be regarded positively in the person living with dementia. Sue shared her belief that people living with dementia were expected to do what other people told them to do which was generally to be quiet and not disrupt other people's activities. People living with dementia should be repositioned as 'active' and have a requirement to be purposeful in their actions, rather than expected to accept a passive role:

> *They need to understand that just because we've got dementia, doesn't mean we are going to go and sit in a corner. We're active. We try our best to do things and we don't like being told 'no', like a two-year old.* (Sue)

The purpose of activity was addressed in Colin's reflection regarding his relationship with the chapel. His work at the chapel created an equally supportive bond between himself, his wife and the other members of the group. This work was acknowledged as having a greater purpose to raise funds for charitable organisations. For the person living with dementia, a meaningful purpose may suggest achievable practical outcomes but is also addressed through the supportive nature of friendships and working relationships. The purpose of activity is likely to be considered more positively by others if they are able to observe its benefits beyond the person living with dementia's individual experience:

> *But the people I work with at the chapel right, it's a network, it's a network for me, it's a network for my wife and it's a network for the whole people. It, it's a bond and they look after, and we reciprocate that by helping raise funds for the different places, you know?* (Colin)

An expectation that people living with dementia are positioned as requiring activities that are meaningful to them was articulated through all four participant's narratives and was regarded as a base level of thinking. Sue's suggestion that people living with dementia were regularly positioned as requiring no activity, other than 'sit(ting) in a corner' suggested that the current lived experience for people living with dementia does not meet this requirement. Although the theme of *Support* demands more of the speaker in the subsequent sub-theme of *Encourage,* the positive acceptance that people living with dementia require meaningful activity is mandatory before speakers can attempt to address the requirements of the second sub-theme.

Encourage

Colin drew on his previously shared Discovery narrative to describe the encouragement and support he had required from his wife on the day of the march. Having his wife in his line of vision, provided him with the encouragement he required whilst also providing his wife with a degree of reassurance that she can provide support to him, if required:

> *Just recently there was a march and I was in the ranks with everybody and my wife was walking on the side and was doing that so that she can keep, 'cause if I can see her in my peripheral vision right, I know where she is and she feels comfortable about that.* (Colin)

Whilst Colin's narrative addressed an activity which he had identified and his wife supported him to achieve, Pauline used her story to illustrate an activity that was instigated by her friend. When offered the opportunity to go on a canoe trip, there was no indication that her friend believed that Pauline's ability to do this was doubted. Being encouraged to take part in the canoe trip was a powerful statement of her friend's belief in her abilities and the requirement to facilitate activities to use her skills. Pauline's admission that the incident made her feel 'normal' also relates this narrative to the *Dementia Unseen* theme:

> *She asked me if I'd like to do it (the canoe trip) and that was good because she didn't decide for me, either I can or couldn't. I was asked would I like to do it…it made me feel normal, like I was before I got diagnosed because a lot of people go on about all the things you can't do now and not what you can still do and I say it's just nice to be asked.* (Pauline)

Drawing on negative experiences, Pauline illustrated that the need for other people to encourage people living with dementia to be involved with meaningful activities does not invite those same people to impose activities that the person living with dementia does not want to do. The four participants described how people reacted to people living with dementia when they did not want to be involved in activity changed, closely aligning this to the Dream theme, *Language:*

> *Oh come on, you'll be alright with us, stop being a misery.* (Pauline)

The sub-theme *Encourage* is more than a recognition of meaningful activity but a demand that other people provide assistance to achieve this need for the person living with dementia. The narratives suggest that the speaker could achieve this through silent, physically present support or more directly through the introduction of activities. The *Encourage* theme does not support activities that are imposed on the person living with dementia, which they do not find meaningful.

5.5 Dementia Unseen

This theme synthesises and articulates the external requirements that describe speakers who are able to position the person beyond their diagnosis of dementia. Two external requirements reside within the *Dementia Unseen* theme. One of these external requirements, *The people know I've got dementia but it doesn't matter* informs the sub-theme of *Doesn't matter.* The sub-theme encapsulates speakers who are aware of the person living with dementia's diagnosis, and may make the person living with dementia aware of this knowledge, but are not influenced by this in regards to the positions they allocate to people living with dementia. The remaining external requirement applied to the theme, *We were treated like we didn't have dementia* is articulated in the sub-theme *No dementia*. This sub-theme illustrates when the person living with dementia's positioning by others is not experientially different from their pre-diagnosis experiences of verbal positioning. Through mapping the theme and sub-themes, the conceptual themes from Dream, *A change in understanding (about dementia and me), Acceptance* and *Who I am* are representative of positive positioning within the *Dementia Unseen* theme.

Doesn't matter

To inform the sub-theme of *Respect* in *Belonging*, Gavin articulated the demand that other people believed him when he shared his diagnosis. Being aware of the diagnosis does not mean that other people should judge the person living with dementia on this information alone. Gavin spoke about the importance of being treated 'like anybody else' even when the speaker was aware that he had dementia:

> *I'm treat down there just like anybody else. They don't make any allowances for me. I just go down. They know I'm not well but they do all treat me just like normal, just like one of the lads. So, that's a better feeling down there.* (Gavin)

Pauline provided direct advice to a specific group in society regarding the need to be aware of the diagnosis whilst not using this to treat the person as inferior to others. This does not mean that the dementia diagnosis is ignored as Pauline suggests that the person living with dementia may require a patient approach, perhaps more so than a person without dementia. Similar, to Gavin's narrative, this need is also aligned to the *Respect* sub-theme in *Belonging* suggesting that this current them would be less likely to positively occur until the latter sub-theme was achieved:

> *Just to be treated as a person. That's what I'd like, with patience and respect.* (Pauline)

The Dream theme *A change in understanding (about dementia and me)* was identified as requiring an element of education to share the experience of dementia and Sue drew on this need to share how she had lived with other people seeing her dementia, before they recognised her personhood. Although, Sue's narrative does not directly demand a particular action, she underlines the power that dementia can have on the attitudes and actions of others, and how these negatively impact on the person living with dementia themselves:

> *It's been difficult. Some people have helped, some people are not very helpful, some people even make you feel worse with their attitudes towards, when you mention dementia.* (Sue)

By identifying the impact of negative experiences when speakers cannot see beyond the dementia and recognising positive experiences when other people were aware of the diagnosis but did not let that knowledge influence their positioning, direct guidance was provided by the people living with dementia to suggest how the theme of *Doesn't matter* could be positively achieved.

No dementia

Being aware of the person living with dementia's diagnosis and not allowing this to influence a speaker's position is the positive outcome in *Doesn't matter* but the group suggested that this positive positioning could be extended further when their experiences were experientially similar to pre-diagnosis events, when their dementia did not exist. Colin stated that his relationship with the chapel group was enhanced as he had never shared his diagnosis with them and therefore they could not be influenced by dementia when verbally positioning him. Colin did not suggest that withholding diagnosis was a solution to inform a positive *No dementia* position but sharing this experience provided an insight into the lived experience of this positive positioning. Pauline extended her demands on health professionals regarding their positioning of people living with dementia, suggesting that although meeting the requirements of positive positioning in other sub-themes, particularly *Respect* and *Doesn't matter,* an absolute positive position would not be achieved until the person living with dementia was treated like 'anybody' else:

> *Any professionals, health, to treat you like, with respect and dignity. Like they would anybody.* (Pauline)

Colin shared his expectation that dementia was not used as a tool to define the person living with dementia by other people. Although he had been a strong advocate for the dementia education proposed in the Dream theme, *Who I am,* he demanded that people recognised that the differences in people living with dementia are not caused by their different diagnoses but, just like everybody else, every person living with dementia is different because they are diverse, individual human beings in their own right:

> *Everyone is different and not just because of their diagnosis. We are all different people.* (Colin)

A demand that other people recognise an individual's dementia but provide them with positions that suggest that they do not have dementia was practically difficult to demonstrate, in regards to direct commands provided by people living with dementia. Colin's suggestion to recognise the diversity in all people, rather than only people living with dementia, was the potential ingression to this positive positioning.

5.6 Positioning themes as a framework for analysis

The four conceptual positioning themes provide a template for positioning theory analysis (Davies & Harré, 1990). All four themes were subject to further thematic analysis (Braun & Clarke, 2006) using the narratives in Discovery and the Dream contributory factors to assess the practical application of each theme as markers for negative and positive verbal positioning. The previous analysis established the four themes as the discursive contexts when people living with dementia are most likely to feel personally affected by the verbal positioning (Davies & Harré, 1990) by other people. Through the comparative analysis, a Balancing Framework has been developed that allows the assessment of the positive power, or otherwise, of verbal positions in the context of the person living with dementia's lived experience.

In the context of the model, Dream factors were observed to have variable status as communication acts, acting as predominantly illocutionary and to a lesser extent, perlocutionary forces. Comparatively, as descriptors of authentic experience with practical outcomes, Discovery narratives were more representative of perlocutionary forces. Each theme is presented with examples from Discovery narratives and Dream factors to illustrate potential illocutionary and perlocutionary forces that would indicate positive verbal positioning within their context. Narratives from Design are used as examples to indicate verbal positioning, in these contexts, which would negatively position the person living with dementia.

Belonging

The Dream theme *Acceptance* includes the factor *I am treated with respect,* which is directly linked to the *Belonging* sub-theme *Respect.* The factor represents the expected positive outcome of verbal positioning which positively disposes the person living with dementia as *Belonging*. A practical example of positive positioning within this theme is observed in Colin's Discovery narrative. Colin describes attending the march and being treated with respect by his wife and the crowds who cheer him and the other armed service members. Colin's wife and the crowd achieve the Dream factor, *I am treated with respect,* which results in Colin experiencing positive positioning in the context of the *Belonging* theme.

The negative experience of *Belonging* is described in Pauline's statement:

> *Don't say 'awwh, bless you'. Just treat us the same. We don't want your pity, so please, just treat us with respect.* (Pauline)

Pauline links infantilisation to a lack of respect towards people living with dementia. This verbal positioning results in the achievement of an illocutionary force opposite of the Dream factor, *I am treated with respect,* meaning that the person living with dementia is positioned negatively in the context of *Belonging* and the sub-theme, *Respect.*

The positive and negative dimensions of positioning within this context are illustrated in Figure 20.

Figure 20: Belonging (Respect): positive and negative analysis

Able

The Dream theme *What I can do* includes the factor *I am asked if I want to try new things. It is not presumed that I can't do them or just won't want to,* which is directly linked to the *Able* sub-theme *Capable.* A practical example of positive positioning within this theme is observed in Gavin's narrative. Gavin describes being able to use a new electronic ticketing system as part of his employed role in the fairground. He is never assumed to lack the capability to do this and is asked by colleagues for his assistance when they struggle to adapt to the new system. By assuming Gavin has the ability to use the new system, his employer achieves the Dream factor, *I am asked if I want to try new things. It is not presumed that I can't do them or just won't want to,* which results in Gavin experiencing positive positioning in the context of the *Capable* sub-theme. The actions of his colleagues result in the positive achievement of the *Superior* sub-theme.

The negative experience of *Able* is described in Pauline's statement:

> *A lot of people go on about all the things you can't do now and not what you still do.* (Pauline)

By identifying what the person living with dementia can no longer achieve, the speaker creates a negative verbal position in the context of the *Able* theme. By achieving an illocutionary force opposite of the Dream factor, *I am asked if I want to try new things. It is not presumed that I can't do them or just won't want to,* the person living with dementia is positioned negatively in the context of both sub-themes in the *Able* theme.

The positive and negative dimensions of positioning within this context are illustrated in Figures 21 and 22.

Figure 21: Able (Capable): positive and negative analysis

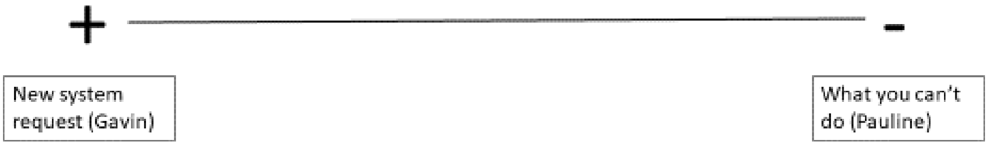
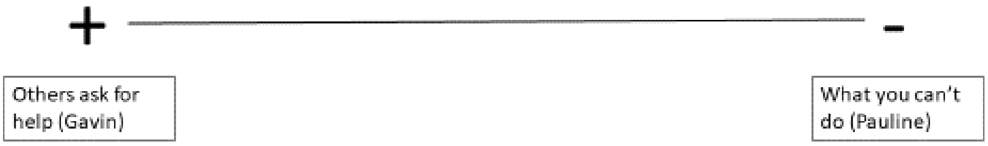


Figure 22: Able (Superior): positive and negative analysis



Supported

The Dream theme *Language* includes the factor *I am not called 'miserable' because I don't want to do something,* which is directly linked to the *Supported* sub-theme *Encourage.* The factor represents the expected positive outcome of verbal positioning which positively disposes the person living with dementia as *Supported*. A practical example of positive positioning within this theme is observed in Pauline's Discovery narrative. Pauline recalled her experience of being asked whether she would like to go on a canoe trip by her friend:

> *That was good because she didn't decide for me, either I can or couldn't. I was asked would I like to do it and when I said yes, that's what we did.* (Pauline)

By encouraging the activity whilst offering no negative consequences for refusing, Pauline's friend achieved the Dream factor, *I am not called 'miserable' because I don't want to do something*, which resulted in Pauline experiencing positive positioning in the context of the *Encourage* sub-theme.

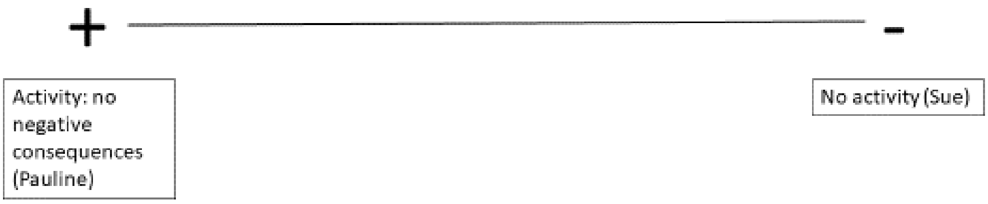
The negative experience of *Supported* is described in Sue's statement:

> *They need to understand that just because we've got dementia, doesn't mean we are going to go and sit in a corner. We're active.* (Sue)

Sue's example suggests an experience were people living with dementia are denied meaningful activity resulting in negative positions in both the *Purpose* and *Encourage* sub-themes of Supported.

The positive and negative dimensions of positioning within this context are illustrated in Figure 23.

Figure 23: Supported (Encourage): positive and negative analysis



Dementia Unseen

The Dream theme *Acceptance* includes the factor *I am treated like everybody else, just like I used to be,* which is directly linked to the *Dementia Unseen* sub-theme *No dementia.* The factor represents the expected positive outcome of verbal positioning which positively disposes the person living with dementia as having their *Dementia Unseen* by others. A practical example of positive positioning within this theme is observed in Gavin's Discovery narrative. Gavin describes his relationship with his colleagues as unchanged by his dementia diagnosis, which he illustrates in Design:

> *I'm treat down there just like anybody else…. They know I'm not well but they do all treat me just like normal, just like one of the lads.* (Gavin)

By being aware of Gavin’s dementia but not allowing this to influence their positioning of him, Gavin’s colleagues achieve the Dream factor, *I am treated like everybody else, just like I used to be,* which results in Gavin experiencing positive positioning in the context of the *No dementia* sub-theme.

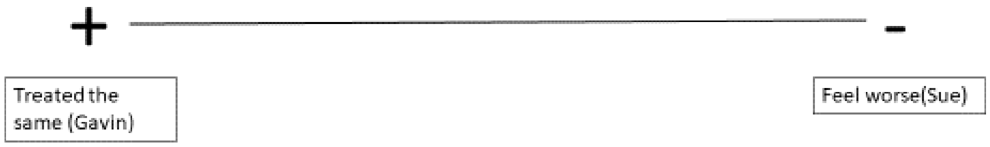
The negative experience of *Dementia Unseen* is described in Sue’s statement:

> *….some people even make you feel worse with their attitudes towards, when you mention dementia.* (Sue)

By focussing on the dementia diagnosis and allowing this to predominantly influence the positioning of people living with dementia, the speaker creates a negative verbal position in the context of the *Dementia Unseen* theme. By achieving an illocutionary force opposite of the Dream factor, *I am treated like everybody else, just like I used to be,* the person living with dementia is positioned negatively in the context of both sub-themes in the *Dementia Unseen* theme.

The positive and negative dimensions of positioning within this context are illustrated in Figure 24.

Figure 24: Dementia Unseen (No dementia): positive and negative analysis



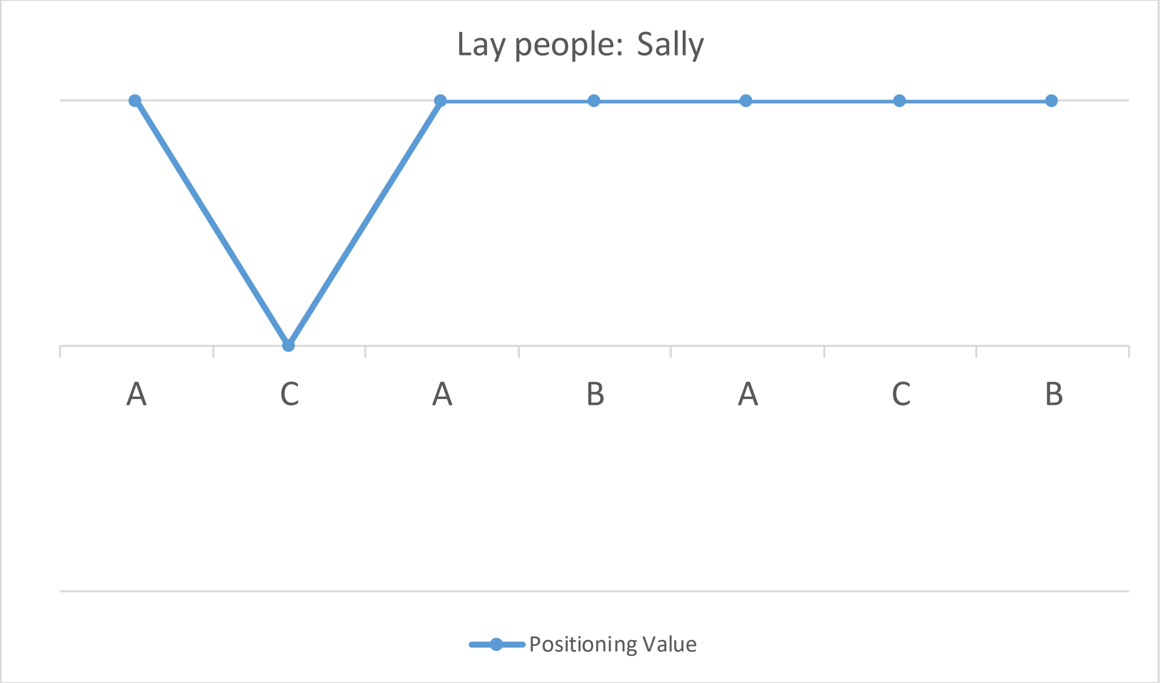
The Balancing Framework

As the thesis required an analysis of whether the positioning of people living with dementia was influenced by viewing the AI film, the development of a framework to indicate positions within the context of the four themes was a priority. The analysis of discourse by the social groups in the next phase of AI was dependent on having this framework. Therefore there was a significant amount of pressure in the development of the Balancing Framework, which was the eventual product of ten months of analysis, reconfiguration and testing. The first part of this development was the thematic analysis to determine how the people living with dementia viewed positive and negative positioning. Once the four themes were developed it was necessary to reverse the analysis and reflexively take the examples of positive positioning used to inform the themes, to test the allocation of this discourse against the four dimensions of positive and negative analysis. This was discussed with the supervisory team as my close familiarity with the data was potentially leading to bias as I was allocating discourse to themes that I had already analysed using the same discourse. Ideally these two periods of analysis would have been completed by two different researchers but the risk of bias was addressed by working through examples of analysis during supervision. This analysis supported the discussions and development of the characteristics of an indicated theme and then, whether a position was considered neutral, negative or positive.

The visual presentation of this data within a framework was difficult to realise as there were no previous examples of illustrating positioning analysis in this way. The visualisation was crucial to understanding the findings, beyond a trite retelling of the analysis. However, during the early analysis, the value of positions was displayed in three columned tables illustrating the three positioning values. This had some value as a mechanism to collect data but its value as an indicator of change was small due to the variation in the numbers of allocated positions within themes between periods of discourse. During supervision we discussed the importance of visually displaying the positioning analysis and this led to several months of attempting various methods of charting. Whilst moving through this process it became evident that whilst the number of positive positions allocated was important, it was by transforming these into percentages within their thematic contexts that changes were more clearly observed. Column, bar and line charts were tested as a means to display the data but each of these appeared to give similar prominence to each of the three positioning values and therefore denied the importance of the positive core. Positioning data as percentages was displayed as circles of different sizes, similar to how the scoping review data had been in Chart 1, but this had too many parts resulting in a lack of clarity.

Individual positions within storylines were entered into line charts, which allowed the discourse to be viewed as a journey of changing positions. The highest line represented a positive position, the central line indicated a neutral position and the lower line indicated a negative position. An example of this from the discourse, from lay people discussing the Sally case study, is displayed in Chart 25.

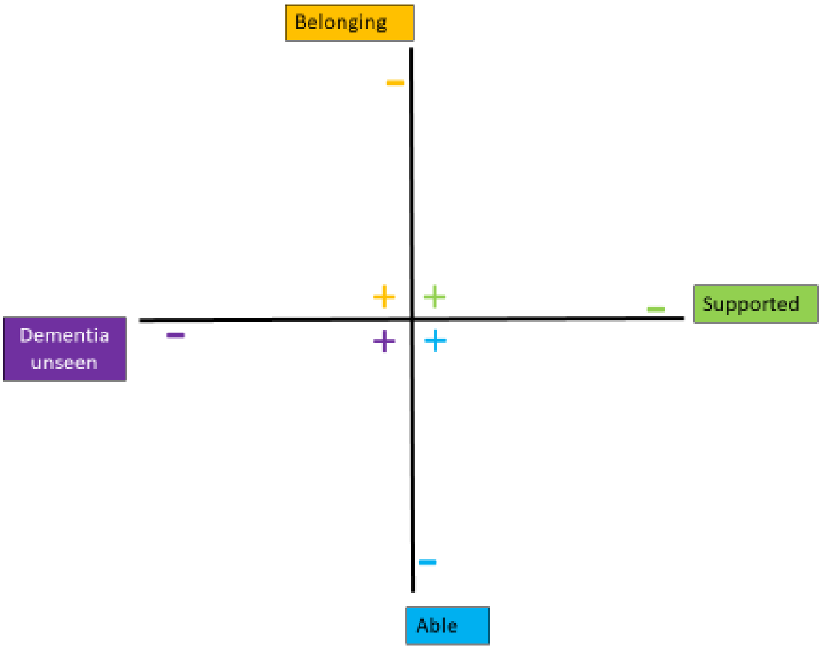
Chart 25: Line chart displaying positions within a storyline



Whilst this charting was helpful in viewing the direction of positions during discourse, it did not allow for a direct comparison between pre and post AI film positions and was overly complex, with charts required for each theme and overall positioning. However, these charts did support the analysis for the findings discussed in chapter 7.

As a mechanism to analyse the positive and negative positions created through discourse, the single thematic models were constructed as a tetrad to display the four positioning themes. This is displayed in Figure 25.

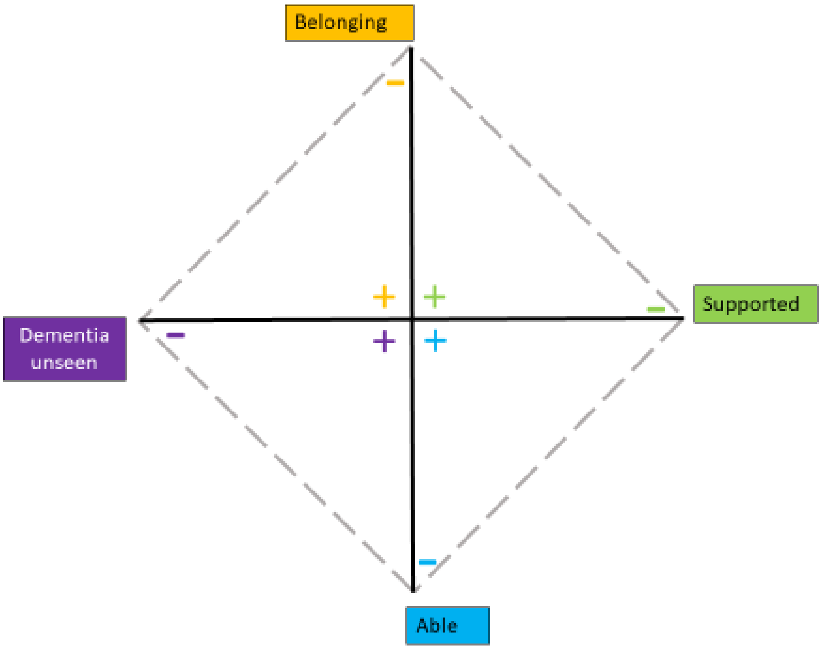
Figure 25: All themes: positive and negative analysis



Placing the individually themed lines indicating dimensions of positive and verbal positioning together as a tetrad was attempted relatively early in the development phase but the practicality of entering data into this model was not attempted until after several months of attempting other methods of charting. Originally, I had observed the tetrad with the positive positions sitting on the end of each thematic line and negative positions at the centre. Having this viewpoint possibly impacted on the development of the Balancing Framework for months. It now appears obvious that the positive positions should be allocated in the centre or core of the framework, as indicators of the positive core described by the people living with dementia. Once these values had moved to their final positions, the visual illustration of positions within the theme was not a straight forward process. If one position was offered and positive this meant 100% of positions were positive within a theme and could be entered as such. Negative positions were equally transferable to the framework. Neutral positions were more problematic and I struggled to find their place within the framework and considered dismissing the tetrad as another failed attempt. Several weeks were spent attempting to enter all three positioning values into the framework and this led to discussions with the supervisory team that I felt the work was not progressing. The key to overcoming this difficulty was returning to the discursive content of the three AI phases and the principles of the methodology. Once positivity was placed at the core of the framework, with other positions entered as not achieving positive positioning, the visualisation of the positioning analysis was made clear. Ironically, my previous criticism that other charts focussed on all three positioning values equally had led me to adopt this viewpoint when developing the Balancing Framework, when this was not necessary. The first time that positioning data was entered into the Balancing Framework and could be clearly visually observed was perhaps the most important theoretical moment of the entire thesis. As a theoretical development it was novel but without it, the analysis of discourse would have not been achieved in the same way. Whilst the months developing the framework included many setbacks and disappointments, the final result justified the necessity of this difficult process.

Discourse that produces a positive position in relation to any of the four themes takes place at the centre of the Balancing Framework. Negative positions are located at the extremities of each thematic line. Markers are added to the framework to illustrate a positive or negative position in relation to the theme. As discourse is fluid and speakers will move between positioning themes and positional qualities throughout conversation, the positivity and negativity of each theme is illustrated by connecting these markers, providing an observation into the positive or negative quality of an individual speaker's discourse or a conversation involving multiple speakers. Positioning that occurs entirely within the positive extremity is located in the centre of the framework. Positioning that occurs entirely within the negative extremity is located at the edge of the model, providing the framework with a fixed boundary. The boundary is displayed in Figure 26, which completes the visual representation of the Balancing Framework.

Figure 26: Balancing Framework



The markers allow the model to be displayed without the thematic lines, with the achieved positional qualities illustrated by linking the markers within the framework. Figure 27 illustrates the Balancing Framework when only positive positions are added to all four themes. The allocated positions are only observed in the central area of the Balancing Framework. The closer the allocated positions are to the centre of the Balancing Framework, the greater number of positive positions have been allocated during discourse.

Figure 27: Balancing Framework: Positive positions

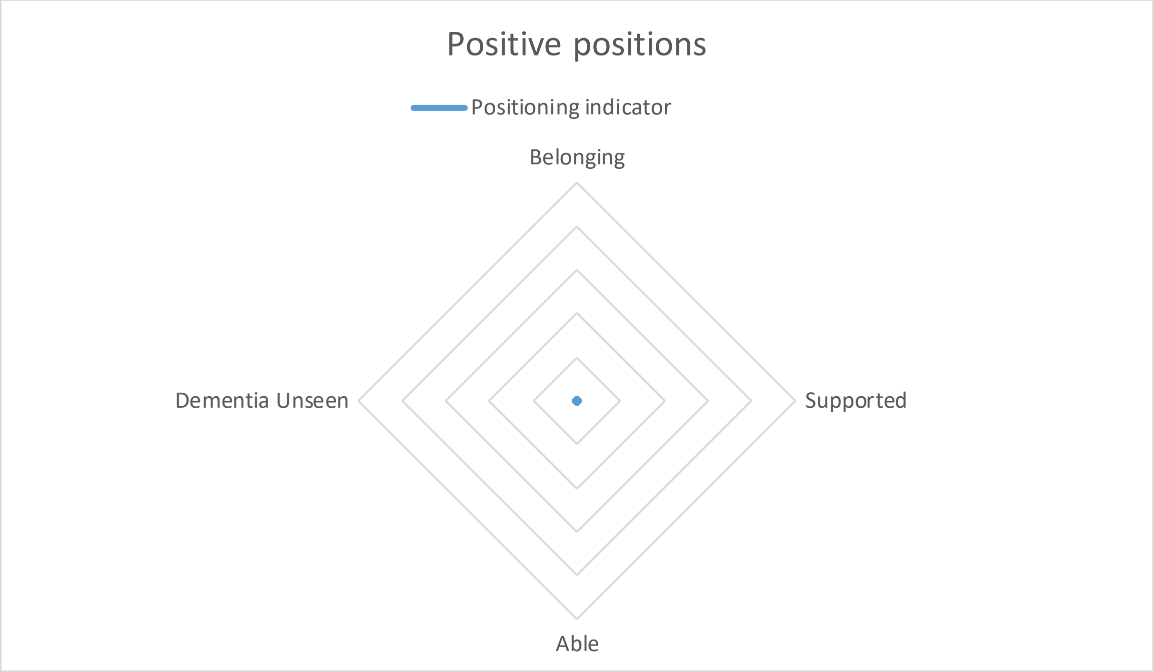
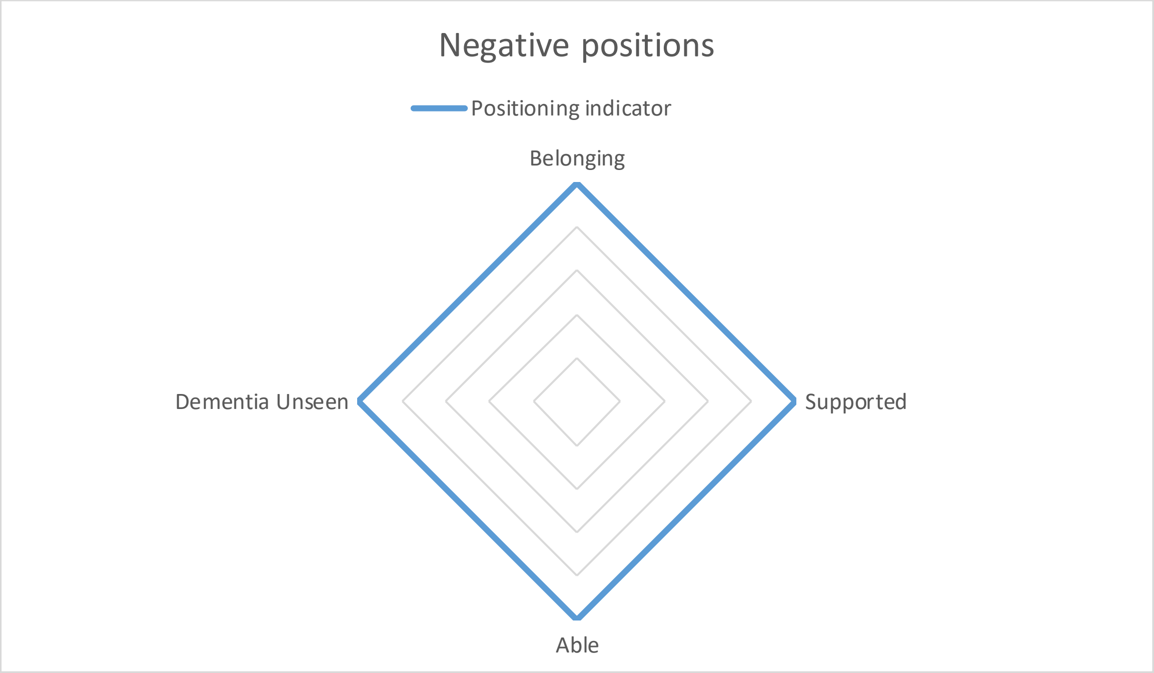


Figure 28 illustrates the framework when only negative positions are added to all four themes.

Figure 28: Balancing Framework: Negative positions



Activating the framework

Verbal statements made in the context of the four positioning themes activate the use of the framework. The four positioning themes are not proposed to encapsulate all possible positions for people living with dementia and therefore positions may be assigned to people living with dementia that would not be addressed through this framework. Only positions that either uphold or deny the external requirements of positive positioning as viewed by people living with dementia are entered into the framework for analysis.

To assess whether a position should be entered into the framework, it must first be analysed in regards to its association with one of the four positioning themes. This initial analysis does not regard the positivity or otherwise of the verbal position but considers whether the statements context is aligned to a positioning theme. This initial analysis is focussed on the locutionary statement itself rather than any illocutionary or perlocutionary outcomes. To identify the relevant positions as contextually relevant, the positive positioning sub-themes are reframed as neutral thematic identifiers, illustrated in Table 13

Table 13: Neutral indicators within the themes

Belonging	Able	Supported	Dementia Unseen
Being like others	Assumptions about abilities	Active	Dementia's influence
Blame	Abilities compared to others	Involve	Dementia as a decision maker

The *Respect* sub-theme from *Belonging* is provided as an example to illustrate how the positive positioning sub-themes are reframed as neutral indicators.

The sub-theme was informed by the external requirements *There were other people around me who had the same respected status* and *Somebody told other people that I should be respected.* The positive position is clearly illustrated through the external requirements, suggesting that positive comparisons with people without dementia, voiced by other speakers creates a positive *Respect* outcome. Contrary to this position, if a person living with dementia is regarded or treated negatively, in comparison to a person without dementia, the outcome is the opposite of the desired position. Although these positions have different outcomes in regards to their positivity or negativity, there is a shared context for each position. Both positions are concerned with comparing the person living with dementia to other people, which provides the context for identifying positions which align to this sub-theme. Although the desired position remains an external requirement for respect, meaning that the negative position would be a position of being treated with no respect, the neutral context is provided by positions that compare people living with dementia with other people creating the neutral indicator, *Being like others.*

Each neutral position has been alphabetically and numerically coded as a mechanism to transpose the data into the Balancing Framework in Figure 26. The reframed sub-themes will now be presented.

Belonging – B1. Being like others

Positive sub-theme: Respect

Statements that compare the person living with dementia to other people.

Belonging – B2. Blame

Positive sub-theme: No blame

Statements that indicate the person living with dementia’s control over their symptoms.

Able – A1. Assumptions about abilities

Positive sub-theme: Capable

Statements that address the speaker’s view of the person living with dementia’s abilities.

Able – A2. Abilities compared to others

Positive sub-theme: Superior

Statements that compare people living with dementia’s abilities to other peoples.

Supported – S1. Active

Positive sub-theme: Purpose

Statements that concern the activities of the person living with dementia.

Supported – S2. Involve

Positive sub-theme: Encourage

Statements that indicate roles for other people in the person living with dementia’s activities.

Dementia Unseen – DU1. Dementia’s influence

Positive sub-theme: Doesn’t matter

Statements that are influenced by the person’s diagnosis.

Dementia Unseen – DU2. Dementia as a decision maker

Positive sub-theme: No dementia

Statements that are directly dictated by or ignore the person living with dementia’s diagnosis.

Analysing the illocutionary intention

Locutionary statements identified as aligning to the context of neutral indicators are allocated to their corresponding positioning theme. These statements are analysed regarding their illocutionary and potential perlocutionary forces to identify whether they fulfil the external requirements for positive positioning within the theme. Positive positions are identified by directly mapping original statements to the external requirement. Positions that do not match the external requirement are analysed to assess whether they create positions that are the opposite to the desired position or if the position is contextually relevant but has an illocutionary negligible or neutral effect. Positions that articulate the opposite of the external requirement are classified as negative positions. Positions that do not oppose or match the positive external requirements are classified as neutral positions.

The external requirement, *It was somebody else who realised that I was capable of doing something and wanted me to do it* from the *Supported* sub-theme, *Encourage* is used as an example to illustrate the identification of positive, neutral and negative positions within the *Involve* neutral indicator. Allocations are illustrated in Table 14.

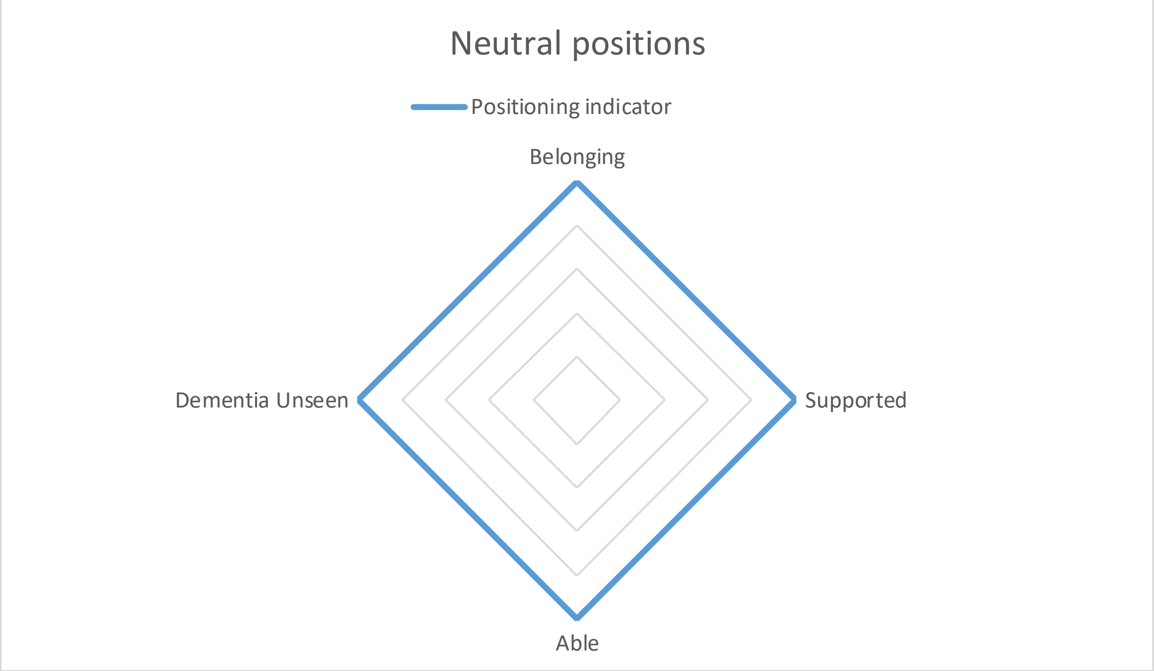
Table 14: Positioning value indicators (Encourage)

The external requirement: Meeting the criteria for positive positioning	Acknowledging the requirement: Meeting the criteria for neutral positioning.	Refusing the requirement: Meeting the criteria for negative positioning
It was somebody else who realised that I was capable of doing something and wanted me to do it.	Somebody else realised I could do something but did not encourage me.	Somebody else did not believe I was capable of doing something.
+	=	-

The positive position is unchanged from the external requirement. The neutral position indicates a possible fulfilment of the requirement, with the speaker continuing to acknowledge that the person living with dementia 'could do something' but lacks the integral aspect of *Encourage*, the position that the person living with dementia is provided with the necessary assistance to be involved with the activity. The negative position denies both the assistance and the belief that the person living with dementia is able to engage.

Although neutral positions may have less harmful perlocutionary effects on people living with dementia than negative positions, it is crucial that they are included in positioning analysis as they are similar to negative positions, as neither fulfil the external requirements of positive positioning. As positions that are unrepresentative of the desired positive positions articulated by people living with dementia, they are similarly entered into the Balancing Framework to illustrate the non-fulfilment of the external requirements. This approach is aligned with AI, which places the focus firmly on affirmative outcomes. Figure 29 illustrates the framework when only neutral positions are added to all four themes.

Figure 29: Balancing Framework: Neutral positions



Neutral positions are identified as non-positive positions in the framework but are displayed separately from negative positions when directly assessing incidents of discourse. These three positioning values remain separately defined to assess positional shifts in individual speakers and groups.

The three positioning values for each of the external requirements, within their positioning theme, will now be illustrated in Table 15.

Table 15: Positioning value indicators (all themes)

+	=	-
The external requirement: Meeting the criteria for positive positioning	Acknowledging the requirement: Meeting the criteria for neutral positioning.	Refusing the requirement: Meeting the criteria for negative positioning
Belonging		
Being like others		
Respect		
There were other people around me who had the same respected status	Other recognise that I am present.	I was not respected like others around me

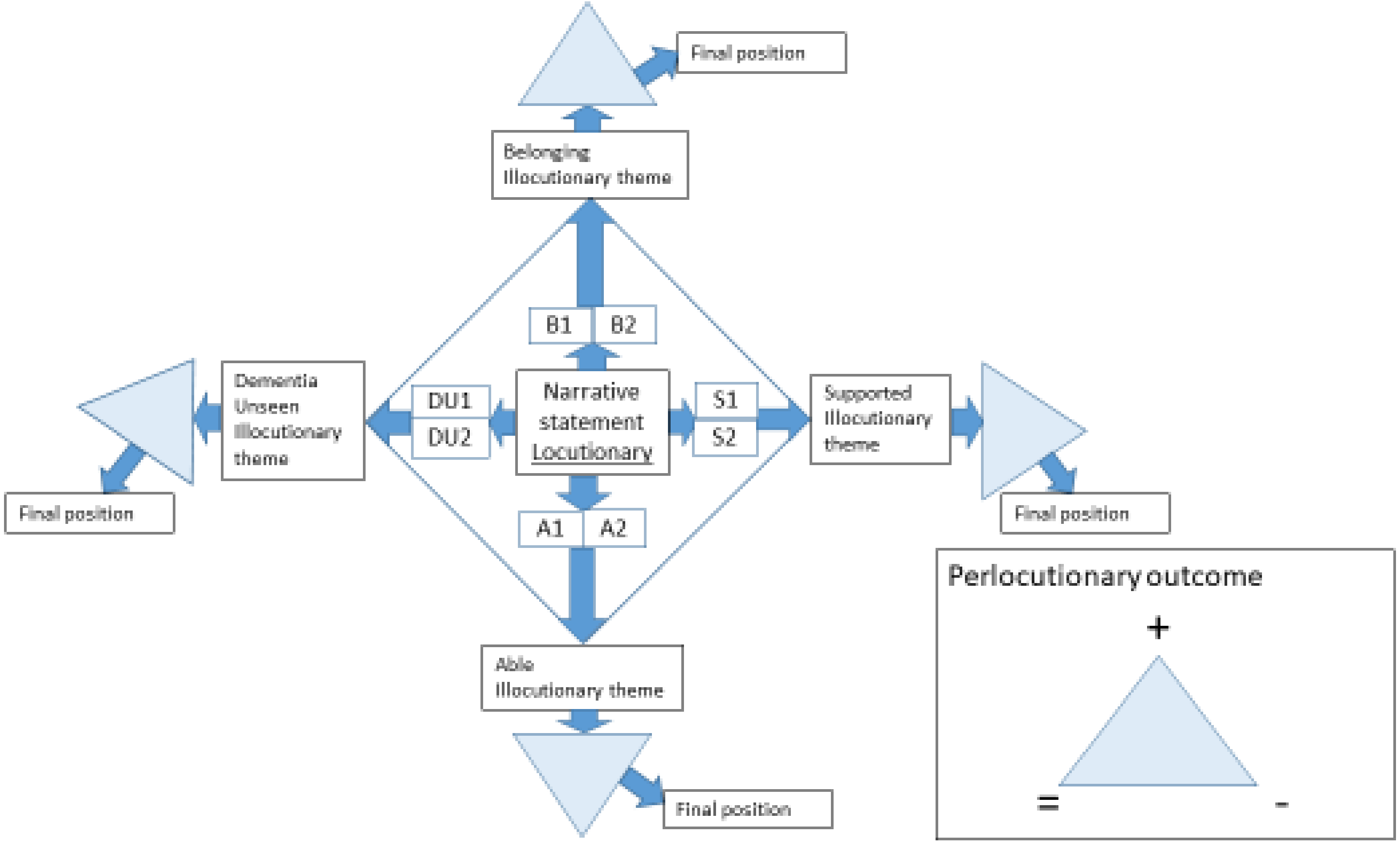
Somebody told other people that I should be respected	No one denied I should be respected	No one said I should be respected
Blame		
No blame	🟧	🟥
If something goes wrong it wouldn't matter	Things go wrong when you have dementia	It would be my fault if something goes wrong
Able		
Assumptions about abilities		
Capable	🟧	🟥
No one assumed that we weren't capable	No one was sure if I was capable	It was assumed I am not capable
Others recognise your competence even when you don't	Others don't recognise my competence	Others deny my competence
Abilities compared to others		
Superior	🟧	🟥
Someone remembered that we can do things that they can't	Someone isn't sure if I can do things	Someone thinks they are better than me at everything
Supported		
Active		
Purpose	🟧	🟥
Others realise I need to have a meaningful purpose in my life	No one stops me from my meaningful purpose	No one thinks I need a purpose in my life
Involve		
Encourage	🟧	🟥
It was somebody else who realised that I was capable of doing something and wanted me to do it.	Somebody else realised I could do something but did not encourage me.	Somebody else did not believe I was capable of doing something.
Dementia Unseen		
Dementia's influence		
Doesn't matter	🟧	🟥
The people know I've got dementia but it doesn't matter	The people know I've got dementia but don't use it against me	The people know I've got dementia and it really matters
Dementia as a decision maker		

No dementia	🟨	🟥
We were treated like we didn't have dementia	We were treated like dementia 'sufferers'	We were treated like dementia, not a person

Positioning analysis model

The final model to illustrate the analytical process for positions to be allocated as positive, neutral or negative within their positioning theme is displayed in Figure 30.The locutionary force is illustrated by the utterance of the narrative statement, which is located in the centre of the model. The statement is allocated to a theme, which commences the illocutionary act as the context for the meaning of discourse. The position is then analysed regarding its positivity, negativity or neutrality, which continues the illocutionary analysis but results in the perlocutionary act or behaviour. The final position identified from this analysis is entered into the Balancing Framework.

Figure 30: Positioning analysis model



To illustrate how the final position is derived from the positioning analysis model, an example from a Discovery narrative is used. The incident when a colleague at the fairground asked Gavin for help when using the new ticketing system will be used as the example.

The allocation of a final position to the Balancing Framework begins with the narrative statement of the speaker, which is located in the centre of the model. This central area represents only the locutionary elements of the statement. The locutionary statement is allocated to a neutral indicator.

In Gavin's narrative, the speaker recognises his own abilities and the need for assistance. He recognises Gavin's abilities as he approaches him to ask for the assistance. The speaker is comparing Gavin's abilities with the ticketing machine against his own and potentially his other colleagues, who the speaker has not approached for help. The positional context derives from the statement of requesting Gavin's help due to his greater ability using the ticketing machine and is aligned to a neutral indicator. The neutral indicator for this statement is:

A2: Abilities compared to others

By accessing this neutral indicator, the statement is allocated to the positioning theme, *Able*. *Able* represents the illocutionary purpose of the original statement and activates the analysis using the relevant part of the positioning values table. By requesting Gavin's assistance the negative position is dismissed as the speaker would not have asked for help if they wanted to present themselves as superior to Gavin. The neutral position is equally dismissed as the speaker has directly identified Gavin as being able to use the ticketing machine. The positive position is achieved as the speaker has recognised that Gavin's ability to use the ticketing machine is greater than his own and potentially other colleagues. The allocation of this position within the positioning values table is displayed in Table 16.

Table 16: Example of discourse allocation to positioning indicator table

Able		
Abilities compared to others		
🟩 Superior	🟨	🟥
Someone remembered that we can do things that they can't	Someone isn't sure if I can do things	Someone thinks they are better than me at everything

This represents the final position and indicates the potential perlocutionary outcome of the original narrative statement. The physical outcome was the assistance provided by Gavin to his colleague. The secondary perlocutionary outcome was the satisfaction and feelings of being 'normal', which Gavin described in both his Discovery narrative and Design contribution.

The final position is now available to be entered into the Balancing Framework as one incident of positive positioning within the *Able* theme.

Positional reactions in relation to the Balancing Framework

The content of discourse may approve or deny the allocated positions to individuals or groups without the verbalisation of an original narrative. This discourse can be achieved through repetition of the original position or through affirmative or negative words and expressions. The Balancing Framework illustrates the occurrence of positional values in relation to the four positioning themes and verbalisations, which approve or deny these positional values and are included in the framework as part of these occurrences. The importance attributed to the occurrence of non-original statements is described in the following example.

In a room of 101 people, one person allocates a verbal position to a person living with dementia. In response 100 people shout 'no' to deny the position. By opposing the position, the 100 speakers reduce the impact of the original speaker's intent and have the opportunity to create new positions. In this circumstance the original position has only occurred on one occasion (1%), If the 100 speakers shout 'yes', they confirm the original speaker's position. This provides the positional value of the original statement with greater power and allocates the larger group's verbalisations as occurrences of this positional value. In this circumstance the original position has occurred once and has been confirmed 100 times. This indicates an overall occurrence of 101 (100%).

As individual narrative statements, these episodes of discourse do not retain any positional power. In the example, the vocalisation of 'yes' or 'no' is irrelevant unless the original speaker's discourse is known. Individually, these statements are inappropriate for analysis but in the context of the larger discourse they have the ability to confirm, strengthen or reject allocated positions. These three positional reactions are presented here with a definition of their place in the Balancing Framework.

Confirmed positions

These positions indicate statements that are made in agreement with a previously verbalised position. Confirmed positions can be voiced through original discourse, when a speaker adds to the content of an existing position in the current discourse. Confirmed positions may also be voiced through affirmative statements (e.g. ‘yes’) or through repetition, when the speaker repeats the original speaker’s statement to confirm their approval of the position.

Incidents of confirmed positions are included in the occurrences related to the positioning theme and positioning value identified from the original narrative statement. These occurrences are entered into the Balancing Framework.

Rejected positions

These positions are aligned with second order positioning (Harre & Van Langenhove, 1999) when the original position, or first order position, is questioned by a second speaker. The rejected position also allows speakers to reject their own positional values. As discourse is unstable and positions fluctuate, a speaker may offer one position and potentially reject this same position during the same narrative statement. Similar to confirmed positions, rejected positions can be voiced through original discourse, when a speaker denies the content of an existing position in the current discourse. Rejected positions may also be voiced through negative statements (e.g. ‘no’).

Incidents of rejected positions are only included in the occurrences of positions if their intent is identified and related to a positioning theme. These occurrences are entered into the Balancing Framework.

Strengthened positions

These positions are vocalised by the original speaker to strengthen their original position. These positions occur when the original position is not confirmed or rejected by other speakers, but the original speaker continues to state their original positional intent. The strengthened position differs from a confirmed position, which is accessible to both the original and other speakers. A confirmed position may also include original content whilst a strengthened position contains content only applicable to the original narrative statement.

Incidents of strengthened positions are included in the occurrences related to the positioning theme and positioning value identified from the original narrative statement. These occurrences are entered into the Balancing Framework.

Entering positions into the Balancing Framework

Identified final positions are entered into the Balancing Framework to illustrate the occurrence of positive positioning within the positioning themes. An example of final positions identified through an imaginary discourse is presented to illustrate how they are applied to the framework.

In this example, seven statements are identified in the imaginary discourse, which match the context of the neutral indicators. Once they have been applied to the positioning analysis model, the final positions are allocated as:

Number of positions relating to Supported: 1
Number of positive positions: 1 (100%)

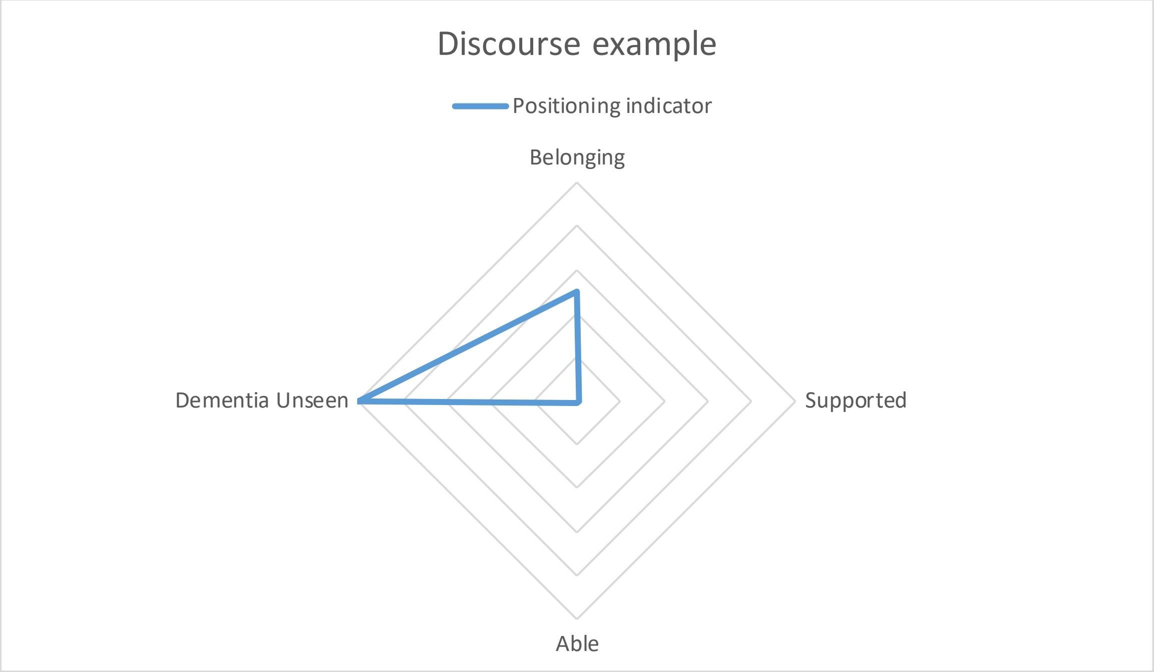
Number of positions relating to Belonging: 4
Number of positive positions: 1 (50%)
Number of neutral positions: 1
Number of negative positions: 1

Number of positions relating to Able: 1
Number of positive positions: 1 (100%)

Number of positions relating to Dementia Unseen: 1
Number of positive positions: 0 (0%)
Number of negative positions: 1

The percentage of positive positions for each positioning theme is transferred to the data sheet in the Balancing Framework. The Balancing Framework in Figure 31 now provides a visual representation of how closely the discourse fulfilled the external requirements of positive positioning. Through the analysis of allocated positions during different periods of discourse involving the same or different participants, it is possible to visualise the achievement of positive positions. It is therefore possible to analyse and visualise positions allocated prior to an individual or group viewing the AI outcome and then directly compare the allocated positions following the viewing.

Figure 31: Example of discourse entered into the Balancing Framework



5.7 Summary

The content of the people living with dementia's Discovery, Dream and Design phases allowed for the development of four positioning themes that are supported by eight sub-themes that align to the external requirements of positive positioning. The positioning themes articulated a Balancing Framework to visually analyse the occurrence of positive positioning within the four themes.

The Discovery narratives provide narrative examples of positive positioning that were used to assess the frameworks applicability to discourse. The demands of the people living with dementia articulated in Design illustrated the negative positions that were equally applicable to the framework. Neutral indicators to activate the model during positioning theory analysis were developed using the external requirements identified by the people living with dementia. These requirements were applied to a positioning values table to identify how discourse could be analysed as fulfilling the relevant positioning theme as a positive, neutral or negative value. A final positioning analysis model was presented, with an example from a Discovery narrative, to illustrate the analysis of a narrative statement, the statements final position and its entry into the Balancing Framework.

The AI outcome for the participants was articulated through the creation of a short film to share their views on how they want other people to verbally position and treat them and other people living with dementia. The depth of their narratives, perceptions of the ideal world and their final Design allowed for a thematic analysis to identify positioning themes that subsequently informed a Balancing Framework. To assess the potential effect of the Design outcome, the positioning analysis of case studies during Delivery required a framework that was informed by the research process and outcomes. The Balancing Framework is concerned with illustrating the positive positions that are articulated by others. As a mechanism to analyse society's closeness to the people living with dementia's Dream and as an outcome of AI, with its foundations in recognising positivity, the Balancing Framework is applicable to any discourse involving or about people living with dementia.

For the aims and objectives of this thesis, the successful development of the Balancing Framework informed the positioning analysis that occurred during the case study discussions in Delivery. The development of the themes and framework illustrate the further generative capacity of the AI process as a mechanism to develop tools to assist in research analysis. The Balancing Framework is central to the analysis in this thesis and could be equally applied to other studies involving positioning theory analysis concerning people living with dementia.

Chapter 6

Findings: Delivery - Verbal positions that are directly influenced by the outcomes of Appreciative Inquiry

6.0 Introduction

This chapter continues to present the findings of the research whilst concentrating on the Delivery of the AI outcome with three social groups. The focus of this chapter is the analysis of whether the people living with dementia were able to influence the verbal positioning of other societal groups through their co-designed AI outcome and how this outcome was influenced by the group's previous experience with people living with dementia. The chapter addresses the aim of the thesis: Can the outcomes of an AI cycle with people living with dementia influence the verbal positioning of other groups in society? The finding discussed is:

3. Verbal positions that are directly influenced by the outcomes of AI.

Finding 3 is presented by exploring the discourse using positioning theory (Davies & Harré, 1990) of three societal groups prior to viewing the AI film developed by people living with dementia, using the case study: Beryl. This discourse is then compared to the discourse of the groups after the film using the case study: Sally, The discussion is structured by examining the positions allocated within each of the four conceptual themes in the Balancing Framework. The positioning theory outcomes are displayed in the Balancing Framework. The Balancing Framework illustrates an overall increase in positive positioning following the introduction of the AI outcome, aligning the discourse of the groups closer to the ideal world vision identified by the people living with dementia in Dream. There are differences in how each group responded to the AI film, regarding how it affected the Balancing Framework.

6.1 Sample

A total of 17 participants consented to participating in the case study discussions. Participants were identified through their affiliation with existing societal groups. Both the healthcare worker and family groups shared experiences relating to their employment whilst the lay people group were socially active together. Demographic details for the groups are presented below:

<u>Healthcare workers</u>

The group consisted of colleagues in a nursing home, specialising in the care and support of older people living with dementia or mental health needs. The researcher met with the group two weeks prior to the empirical research taking place and provided the participants with the research information sheets and consent forms. Consent forms were completed on the day of the research. A debriefing session followed the completion of the case study discussions and a dementia education session was delivered three days afterwards with the group, as stated in the ethical process. A summary of the participants is included in Table 17.

Table 17: Summary of Healthcare worker participants

Participant	Employed role	Years of experience in dementia care	Gender
HWA	Support worker	1	F
HWB	Support worker	2	F
HWC	Senior carer	5	F
HWD	Support worker	2	F
HWE	Senior carer	6	F
HWF	Support worker	2	F
HWG	Support worker	Less than 1 year	F

Lay people

The group met weekly to play Whist in a local church. The group also attended the same church together. The researcher initially met with the group five months prior to the empirical research taking place and provided the participants with the research information sheets and consent forms. The empirical research was delayed due to logistic and personal circumstances at the time. The researcher met with the group again to discuss the research, two weeks prior to the case study discussions taking place. Consent forms were completed on the day of the research. A debriefing session followed the completion of the case study discussions and the dementia education session was declined in line with the ethical process. A summary of the participants is included in Table 18.

Table 18: Summary of Lay people participants

Participant	Relevant experience	Gender
LPA	Spent 3 years as a home carer	F
LPB		F
LPC		F
LPD	Father lived in a warden controlled bungalow (he did not have dementia)	F
LPE		F
LPF		F

Family members/carers

This group were colleagues, working in a museum. The researcher initially shared the information sheets and consent forms with the group following an online discussion. Consent forms were completed on the day of the research. A debriefing session followed the completion of the case study discussions. The group had already arranged to attend an Alzheimer's Society Dementia Friends session following the completion of the research and therefore declined a dementia education session, in line with the ethical process. A summary of the participants is included in Table 19.

Table 19: Summary of Family member/carer participants

Participant	Relative with dementia	Gender
FA	Mother Father-in-law	M
FB	Mother Father Grandmother Father-in-law	F
FC	Mother	F
FD	Close friend Father-in-law	F

6.2 Beryl

The development and content of the case study 'Beryl' is detailed in section 2.4.2.

6.2.1 Beryl: Belonging

The healthcare worker natural discussion group was completed on 02.04.2019. As the development of the Balancing Framework was still ongoing at this time, the discourse could not be immediately analysed but was transcribed in the following week over a period of three days. This was the first discourse to be analysed using the Balancing Framework outside of the testing phase. Analysis was undertaken using the transcript and video of the group, with the video used less as I became more familiar with the data. I was anxious that the discourse, which I knew offered positions for people living with dementia, may not align with the themes within the Balancing Framework. Having established a clear model of analysis (see Figure 30) made the process relatively easy to navigate, even if the allocation of positioning themes and values was sometimes difficult.

Allocating positioning themes and values involved repeated analysis of the same text. Each analysis was completed on clean transcripts, so that I would be unaware of how I had previously allocated discourse. Whilst this was a time consuming analysis, it allowed me to examine several analyses of the same discourse to ensure that the allocation of themes and values was consistent. By maintaining the process illustrated in the positioning analysis model it was possible that each position could be traced back from its values, theme and sub-theme to the original locution and vice versa. This process was used to illustrate the analysis to the supervisory team, who were able to advise regarding discourse which was inconsistently analysed between transcripts.

Healthcare workers

A total of 25 positions were identified within the Belonging positioning theme. Positive positions accounted for 4% (1), neutral positions 40% (10) and negative positions 56% (14).

Negative positions in this theme are commonly derived from verbal exchanges that denied the *No blame* sub-theme. The participant's discussion regarding the daily visit from a carer to check that Beryl had taken her medication suggested that surveillance was required as Beryl may attempt to deliberately mislead others regarding her medication compliance:

> *HWA:*
> *Or if she doesn't take it when they're seeing her. They're going to check that she's taken her tablets. They can see if her tablet's gone but they don't know where it is.* (Belonging -)
>
> *HWB:*
> *Yeah, if she's holding it in her mouth.* (Belonging - Confirmatory)
>
> *HWA:*
> *Or if she hasn't put it in her mouth. They hide them anywhere.* (Belonging – Confirmatory)

The discourse developed from allocating Beryl's position to create a position for all people living with dementia. HWA's use of the word *'they',* positions all people living with dementia as potentially deceptive when taking medication. Conversational aims include the creation of socially determinate actions wherein individual speech actions become determinate speech acts when agreed by other participants (Davies & Harré, 1999). Through the confirmation of negative positions, the speakers have agreed a socially determinate position for people living with dementia as untrustworthy or deserving blame.

By following the positioning analysis model (see figure 30), the first stage of analysis is the identification of a neutral indicator (see Table 13). The discourse in this example was potentially related to the Assumptions about abilities sub-theme, as it alluded to the ability to accept or take medication. The sub-theme of Blame was also evident as there was an indication that the person may deliberately hide medication. I had attached both sub-themes during the analysis over several transcripts resulting in an inconsistent analysis. The potential relevance of either sub-theme justified my decision to look further along the analysis model to the positive value indicators (see Table 15), which indicated the allocation of the Blame neutral indicator more clearly. The negative indicators of each sub-theme were key to this analysis as the accusatory features of the discourse aligned more closely to the Blame sub-theme than the values of the Capable sub-theme.

Whilst discussing potential areas of deterioration due to her dementia diagnosis, the participants suggest that Beryl, through her own inaction, will contribute to her deterioration:

HWF:
She might not, she might not be the type of person who doesn't want to get up and do stuff, she might.. (Belonging – 2nd)

HWB:
And then they get used to that then. (Belonging – Confirm)

HWB:
Don't they! They don't get back to.. (Belonging – Confirm)

HWA:
If you don't use 'em you lose 'em. (Belonging – Confirm)

Through confirmatory positioning the participants create a further socially determinate position for all people living with dementia, with people living with dementia blamed for expediting their deterioration. The adage '*If you don't use 'em you lose 'em',* is directly applied to suggest that people living with dementia are deteriorating due to their own inaction.

Similar to the previous position, a position is offered, which blames people living with dementia for exacerbating their deterioration. Here, the position is unconfirmed as neutral positions are offered, in recognition that deterioration occurs in dementia without blame:

HWA:
She may isolate herself. (Belonging -)

HWA:
Become more depressed. Or become depressed. (Belonging =)

HWC:
Erm, like, health. She might decline in her health needs. (Belonging = Confirm)

HWA:
Yeah, might affect her dementia. (Belonging = Confirm)

Blame is attributed to all people living with dementia as self isolation results in a lack of social activity. A position recognising social stimulation as the means to be like others, aligned to the neutral aspects of the *Respect* sub-theme, acknowledges the need without positive or negative implications:

HWA:
They tend to isolate themselves. (Belonging – 2nd)

The position created by the statement:

HWE:
I do think that it's safe for Beryl to be left alone. (Belonging + 2nd order)

could be aligned to positive *Able* positioning in isolation. Within the discourse, this statement supports the positive criteria for *Respect*, as the speaker considers that Beryl should be given the same opportunities to live alone as other people living in warden-controlled accommodation who are receiving regular support. This statement represents the only occurrence of positive *Belonging* positioning in the healthcare worker group.

Lay people

The lay people natural discussion group was completed on 20.09.2019. This period coincided with the analysis of the healthcare worker group discourse, which was prioritised over transcribing the lay people video. The lay people transcripts were completed over a period of three weeks following the discussion group. Although I had become more comfortable with the process of analysis, I felt less familiar with this group's data due to transcription being completed over a series of weeks rather than the more intense immersion I had experienced with the healthcare worker group. However, despite my concerns that this would make the analysis more difficult, it was reassuring that the positioning analysis model (see figure 30) provided a clear process to the analysis and demanded that each element of the analysis was scrutinised. During this analysis, my anxieties regarding the applicability of the Balancing Framework themes to group discourse were placated and I was confident that the discourse of the next group (family members/carers) would also be valid for analysis.

A total of 35 positions were identified within the Belonging positioning theme. Positive positions accounted for 3% (1), neutral positions 46% (16) and negative positions 51% (18).

The suggestion that people living with dementia require their presence to be acknowledged by others by ensuring their involvement with other people aligns to the *Respect* sub-theme:

LPA:
Because she'd meet other people. (Belonging =)

LPB:
And what would Beryl do there?

LPC:

Well, she could do crafts or.. (Supported =)

LPB:

Well, meet other people..it's the important thing to.. (Belonging =)

LPC:

Meet other people.. (Belonging = confirmatory)

LPA:

And meet other people. (Belonging = confirmatory)

The discourse positions Beryl as needing to be with other people like her but only in the context of her dementia (meet people at a day centre). The positions align to the neutral conditions for *Respect*, as the need to be present with others is acknowledged without the consideration of Beryl's individuality or the position of respect expected in these new relationships.

Negative positions are presented through the *No blame* theme.. The risk of Beryl leaving the house is reframed to suggest that she deliberately causes difficulties to go out *'sneaking'.* Equally, the discourse suggests that Beryl should not be leaving the house, that any attempts to leave the house are preferably thwarted and any harm that befalls Beryl at this time will be due to her own actions:

LPE:

And there is so much, in place, they can put as well. There's if she has, if she has, assessed better. You know if she's going out, sneaking, they can, they can put cameras in..and what it does, they, they..Did you put that for your dad? (Belonging -)

The barriers suggested to prevent Beryl leaving are extended to suggest that to prevent her causing harm to herself she should be locked inside her home:

LPA:

Well I would think, I would think the warden would make sure every night that they're locked in. (Belonging -)

LPB:

Oh, locked in? (Supported = 2nd)

LPA:

Well, erm, keyed in then..I don't mean locked. (Belonging – 2nd)

LPB:

Oh, like, yeah, suppose, yeah. (Belonging – Confirm)

This negative positioning is countered by HWB who is shocked by the suggestion but then agrees with the social action when their neutral position is countered again. However, the negative counterpoint does not alter the semantic meaning of the first negative position (*'locked in'* to *'keyed in'*). The confirmation of the negative position creates the social determinate that Beryl should be prevented from causing harm to herself through an action were she would be considered blame-worthy, without contemplating the potential harm that the preventative actions of others may cause.

<u>Family members/carers</u>

The family members/carers group was completed on 04.12.2019. I was able to transcribe the data immediately and this was completed over a period of two days. I had become more comfortable with the process of analysis and was able to identify the elements of the positioning analysis model (see figure 30) with greater consistency across transcripts, although discrepancies were still observed that required discussions with the supervisory team.

A total of 8 positions were identified within the Belonging positioning theme. Positive positions accounted for 12% (1), neutral positions 38% (3) and negative positions 50% (4).

A negative *No blame* position is created through a discourse relating to disagreements between people living with dementia and carers. Many positions are intended for all people living with dementia rather than Beryl. By acknowledging the person living with dementia's unfavourable reaction to disagreement, they are positioned as making the situation worse:

> *FD:*
> *Because, they'll turn on you and..* (Belonging – 2nd)
>
> *FB:*
> *You've just got to go with the story, haven't you? Be on a boat with dad to Liverpool every time.* (Belonging = 2nd)

The neutral second order position suggests that rather than blame the person living with dementia for their reaction, the reaction should be avoided by understanding the reality of the person living with dementia at that time. This neutral position aligns with the *Respect* sub-theme through its recognition of the person living with dementia's presence and reality. It does not achieve a positive value, as the created position suggests that the person living with dementia is placated by agreeing with their viewpoint during disagreements but does not recognise the potential for carers to alter their own standpoints through the influence of people living with dementia.

A negative *No blame* position is illustrated when potential symptoms of dementia are reframed to suggest deliberately deceptive behaviour:

FD:
What is sometimes, is that they hide things and you can't find things. (Belonging – 2nd)

The misplacement of objects is a clinically significant symptom in dementia, with McGarrigle, Howlett, Wong and Stanley's, (2019) study considering aligned therapeutic targets to increase the well-being of people living with dementia and their carers in relation to this symptom. In this position the symptomology of losing items is regarded as a deliberate misplacement and therefore the person living with dementia should be blamed when an item cannot be located.

The relationship between a partner and their spouse with dementia is addressed in the following position:

FB:
It's very difficult for the partner, isn't it? It's worse. (Belonging –)

The person living with dementia is positioned as being less affected by their diagnosis, suggesting that there is greater value in recognising the presence and offering respect to the partner, compared to the person living with dementia.

6.2.2 Beryl: Able

Healthcare workers

A total of 36 positions were identified within the Able positioning theme. Positive positions accounted for 22% (8), neutral positions 44% (16) and negative positions 33% (12).

The transience of positions during discourse is well illustrated in movements between neutral and positive *Able* positions:

HWD:
So, she's not walking up that hill. (Able =)

HWB:
So she's still doing her own shopping (Able +) *just with a little bit of help.* (Able =)

All three positions are aligned with the *Capable* sub-theme. The first neutral position suggests that although Beryl may retain the capability to walk up the hill, she should not be doing this. Beryl is positively positioned as being able to shop for herself, but is then neutrally positioned by adding the caveat of requiring exterior support to achieve this.

Neutral positioning within this sub-theme is continued as participants discuss Beryl's possible abilities:

> *HWA:*
> *'Cause she used to go out a lot before, didn't she?* (Able =)
>
> *HWD:*
> *She might be able to do things, that she did, does like.* (Able = Confirm)

The positioning by the healthcare workers shows an appreciation that Beryl has been capable in the past and acceptance that these capabilities may still be present but does not confirm a belief in her ongoing abilities.

The neutral position is also applied to other people living with dementia, with the healthcare workers positioning the people living with dementia in the care home, using the same positioning value:

> *HWC:*
> *So what if she doesn't want, like, we've got the likes of some of them here that won't actually. They won't ask for help. The likes of like 'I don't need it'.* (Able =)

The neutral positions applied to the people living with dementia from the care home are aligned to the *Superior* theme. The people living with dementia are perceived as having a lack of insight regarding their abilities and are therefore positioned through their reliance on the healthcare workers to achieve these abilities for them.

The potential lack of insight in people living with dementia is used to negatively position Beryl:

> *HWB:*
> *Well, if she thinks she's independent..* (Able-)

The statement creates an assumption within the discourse that Beryl can only think that she is independent, rather than actually be independent. Beryl's lack of capability is seen as a potential risk as she lacks the insight to envision how her misplaced belief in her abilities could eventually lead to harm.

Doubts regarding Beryl's capability to maintain her basic activities of daily living are alluded to when considering if the carer's daily medication call would be sufficient for her needs:

> *HWA:*
> *Especially if she can't like, taking herself to the toilet..I know she can do that but she might not be able to go to the toilet or like clean herself up properly or make her food. I think it just depends. I think she needs someone going in.* (Able – 2nd)

The participant does suggest that the position she has described for Beryl could be challenged (*'I think it just depends'*) although no other members of the group attempt to reposition Beryl within a positive positioning value.

Lay people

A total of 53 positions were identified within the Able positioning theme. Positive positions accounted for 21% (11), neutral positions 0% (0) and negative positions 79% (42).

Although negative values dominate the Able positions in this group, the acknowledgement of Beryl as positively *Capable* does occur:

> *LPA:*
> *She's obviously not that serious because she, she get, got the bus.* (Able + 2nd)

The position is created by making an assumption about the stage of Beryl's dementia, with the assumption of an earlier stage leading to more positive discourse regarding her abilities. This positioning is revisited in a later conversation:

> *LPE:*
> *You know, she used to meet her friend in the town centre but, it has, has only been unable to do it because the bus service is…* (Able + 2nd)
>
> *LPD:*
> *'Cause of the bus service.* (Able + Confirm)
>
> *LPD:*
> *So, she could carry on with..* (Able + Confirm)
>
> *LPD:*
> *She could carry on with that if she was prepared to pay for a taxi or something, couldn't she?* (Able + Confirm)

Beryl's inability to meet her friend in town is positioned as the consequence of the disrupted bus service. Although the latter factor has incapacitated Beryl's ability to meet her friend, Beryl is not positioned as having a lack of ability herself. This discourse proposes that if the bus service continued to run, Beryl would remain capable of using the service. Equally, the limitation on the proposal that Beryl could use a taxi service to travel to the town centre is her willingness to pay rather than a judgement that she is incapable of doing this.

Positive *Able* positioning acknowledges the potential deterioration for the person living with dementia through discourse relating to seeking assistance:

> *LPA:*
> *Well, there's the phone isn't there, obviously?* (Able + Strengthen)

Although the deterioration is accepted, the position suggests that Beryl would retain the insight into her current condition and the ability to use the telephone to call for assistance.

Attempted positive positioning regarding Beryl's ability to walk to the local shop becomes negatively valued due to the assessment of her abilities once she arrives there:

> *LPB:*
> *And, erm, and, and the small shop she obviously, it's , it's just long enough for her to walk there for a paper or whatever it is. If she can remember which one she reads but I, I think she should live on her own. Be independent up to the point of when she can't.* (Able –)

By doubting Beryl's ability to recall which newspaper she reads, a negative position is achieved, despite other positive suggestions included in the dialogue (*'I think she should live on her own'*).

Decisions regarding Beryl's living situation suggest a negative *Capable* position:

> *LPD:*
> *I don't think she should be, I don't think she's safe.* (Able – Confirm)
>
> *LPE:*
> *What do you think would help. Oh no, she's not safe without..but she's in warden..* (Able – Confirm)

Beryl's inability to independently maintain her safety is used to justify suggestions that she should not be living in her current abode. *'Safe'* is used without further elaboration during sections of discourse although elsewhere, illustration about how her perceived lack of ability is detrimental to her safety is explored in finer detail:

> *LPC:*
> *But you can't rely on a neighbour..can you?....She needs...she needs care (*Able –)
>
> *LPA:*
> *No, you can't rely on a neighbour. She needs another care..., another carer at least. Another carer at least.* (Able – Confirm)

LPB:

Another carer.

LPA:

At least maybe to see if she's eaten. (Able – Confirm)

LPC:

She should have a care…

LPA:

And..she..she..to go to bed. (Able – Confirm)

LPC:

At least twice a day, if not three times a day. (Able – Confirm)

LPA:

Another one……yeh. To help. 'Cause she's burnt herself with that… (Able – Confirm)

The discourse includes activities of daily living, where Beryl is assumed to have lost her abilities. Being unable to feed herself or take herself to bed are situations used to justify Beryl's need for increased carer calls during the day. Beryl is positioned as having placed herself in danger when attempting to use her diminished abilities (*''Cause she's burnt herself with that'*). Assumptions regarding her lack of ability in meal preparation are measurable against assumptions that she retains the ability to arrange a taxi service as they are considered Beryl's possible capabilities. *''Cause she's burnt herself with that'* is verbalised in the past tense suggesting a factual occurrence despite no evidence of this incident appearing in the case study. By using a past tense, the negative position is given greater strength as it insinuates that this incident has already occurred and can be used as evidence to position Beryl within the negative value.

The group uses their concerns regarding Beryl's safety as the catalyst for negative *Able* positioning:

LPA:

What d'you think might happen to Beryl..Well I'd be scared to live in the south, case she leaves something on, cooker or something. (Able – Confirm)

LPB:

Hmm (in agreement) (Able – Confirm)

The potential of a fire risk is used, predominantly by LPA, to suggest why Beryl is not safe in her current situation. When asked for further clarification regarding the group's decision that Beryl requires 'a little more care', the potential for Beryl's lack of ability to cause harm in this way is used to create a negative position:

LPA:

Just to check she hasn't left the blummin' pan on (laughs), check she's alright.
(Able -)

LPD:

Check she's alright. *Check she's eaten.*
(Able – Confirm)

LPF:

And also, maybe help her..erm, making sure she's dressed and undressed and able, ready for bed and stuff and personally, I think eaten as well. (Able – Confirm)

LPA's laughter following her comment strengthens the negative position. The laughter in this instance is not used to ridicule the risk of fire or Beryl herself but represents LPA's belief that this is a straightforward answer to the question, suggesting that this position does not only apply to Beryl but to other people living with dementia as well.

Family members/carers

A total of 15 positions were identified within the Able positioning theme. Positive positions accounted for 7% (1), neutral positions 7% (1) and negative positions 86% (13).

Negative positions dominate the *Able* theme in the group, although on one occasion an assumption of Beryl's incapability is challenged to create a neutral position:

FB:

And yes, won't be eating. (Able -)
Doesn't mention anything about not eating, just about the tablets. (Able = 2nd)

Although the challenge does not assume that Beryl is capable, therefore establishing a positive *Capable* position, it does suggest that incapability should not be equally assumed without supporting evidence.

The impact of Beryl's assumed incapability on potential risks is considered, resulting in further negative positioning within the *Capable* sub-theme:

FD:

No, for me, because if she is dementia, because she could leave the cooker on, forget and things like that. (Able -)

The potential risks in this position are applied to other people living with dementia (*'because if she is dementia'*) as the speaker uses the diagnosis to imply a lack of ability that is shared by all people with a similar diagnosis. The position alludes to the negative positioning values observed in the *Dementia Unseen* theme, although within the discourse the positional impact has greater meaning within the *Able* theme.

The discourse developed to suggest probable changes required for Beryl regarding her current living situation:

> *FD:*
>
> *To go there for ten minutes, give her the tablets and abandon her afterwards.* (Able – Strengthen)
>
> *FA:*
>
> *It's not going to work. (Able – Confirm)*

The suggestion that Beryl is '*abandon*'ed once her carer leaves indicates a position that when left alone she is incapable of sustaining herself and the situation is doomed to fail. Although the negative value of the sub-theme *Superior* is implied in the majority of negative *Able* positions, this is more clearly expressed when people without dementia are included in the narrative. The carer is accepted as having superior abilities to Beryl regarding her medication compliance but this is extended to suggest that Beryl will fail in all aspects of her daily life, due to her inferiority, without the carer's continual input.

The discourse continues to suggest that Beryl lacks the ability to remain in her bungalow for much longer and should be placed in 24 hour care:

> *FD:*
>
> *I don't think you can have a carer that would watch twenty-four hours with dementia. To tell the truth, they'd have to go into a home.* (Able – Confirm)
>
> *FA:*
>
> *It would be difficult to see her staying on her own in the bungalow.* (Able – Confirm)
>
> *FC:*
>
> *For long.* (Able – Confirm)
>
> *FA:*
>
> *Yes, without her going into a home or that she had family living with her. Being on her own she only has ten minutes everyday so I can't see it carrying on that she would be on her own in the bungalow for longer.* (Able – Confirm)

The decision to place Beryl in 24 hour care is dependent on her relationships with other people. Without 24 hour carer support she is considered incapable of living at home. If her family lived with her, she would be able to live at home although her own abilities are regarded as irrelevant when making this assessment. Beryl is negatively positioned in the

Capable sub-theme with further allusions to the negatively valued *Superior* position, as decisions are based on the availability of others rather than Beryl's own abilities.

One positive position in the *Able* theme is observed when the group discuss a television programme, which some of the participants watched involving people living with dementia working in a restaurant:

> *FC:*
> *But they could maybe cook.* (Able + 2nd)

The statement implies the retention of abilities although this positioning remains in the context of the television programme and does not influence how the group considers Beryl's situation or other people living with dementia during the overall discourse.

6.2.3 Beryl: Supported

Healthcare workers

A total of 28 positions were identified within the Supported positioning theme. Positive positions accounted for 18% (5), neutral positions 71% (20) and negative positions 11% (3).

The dominance of neutral positions in this theme is indicative of discourse, which suggests that meaningful activity and the provision of this activity are important for Beryl and people living with dementia without the positive acknowledgement of the possibility this is already independently occurring. Neutral positions are more likely to suggest that there is the potential for meaningful activity to occur:

> *HWF:*
> *And if the support worker had a car then she could get her to the shops to keep..up..keep having to do things by herself.* (Supported = 2nd order)

The support suggested could be aligned to positive positioning in the *Encourage* sub-theme but only achieves a neutral position as the proposed solution creates the dependence on the support worker without the consideration of how Beryl could be encouraged to achieve her needs independently.

This neutral position is observed again through the statement:

> *HWB:*
> *Letting her do what she already does and just supervising.* (Supported =)

Although this position supports Beryl's need to continue her meaningful activities, the introduction of supervision without justification results in the discourse not meeting all the requirements of positive positioning within the theme.

Further support is suggested but without considering Beryl's concept of meaningful purpose:

> *HWD:*
> *Rather than walk up the steep hill to go up the shop she can get..and they..* (Supported = confirm)

> *HWC:*
> *It's someone with her as well, isn't there?* (Supported = confirm)

The group have assessed the walk to the local shop as potentially hazardous for Beryl and have therefore suggested a support worker can drive her to the larger town shops. When making this assessment, they have not considered whether Beryl wants to avoid the local shops and lose the potential social and physical health benefits this journey may provide. The neutral position is achieved as the group consider that Beryl requires meaningful activity but the assessment is driven through the context of risk rather than the individual view of meaningful purpose.

The discourse regarding shopping is explored further when discussing Beryl's attendance at the day centre:

> *HWB:*
> *Yeah, 'cause they can do things like shops in them, can't they? Where you go shopping?* (Supported –)

The group suggest that if a support worker is unavailable, Beryl should avoid independently going to the local shop but should act out her shopping trip at the day centre. Although the group suggest this will allow Beryl to continue the act of shopping, the solution does not consider whether Beryl would find this substitution meaningful and therefore creates a negative position in the *Encourage* sub-theme. Beryl is provided with the means to pretend to go shopping but is denied the possibility to actually attend to this task in reality at the local shop.

Pretence and possible deception are regarded as potential mechanisms to encourage Beryl's attendance at the day centre:

> *HWE:*
> *Like, some people do think they've come to like a hotel so that might be something, that kind of impression that's been put on Beryl to go if she doesn't want to go, erm, yeah. Yeah, have dinner.* (Supported -)

HWE recalls the experience of people living with dementia in the care home who feel they are staying in a hotel and uses this to suggest that the same approach could be used with Beryl if she is reluctant to attend the day centre. The deception is considered reasonable as Beryl can have a meal provided whilst she is there. The decision does not suggest how this deception supports Beryl to envision or meet her own concept of meaningful purpose.

Positive positioning is observed, although not attached to Beryl, as HWB recognises that the meaningful purpose of the care home residents may require stepping into a different reality:

> *HWB:*
> *So, we'd have to say it would be like the next three stops and she'd go and sit down and wait and er..try and..get..You just..try..just enter their world rather than trying to bring 'em down to like where you are, you go to like where they are.* (Supported + Confirm)

This situation is different to the suggestion that Beryl could be justifiably deceived into attending the day centre as in this latter position, it is the person living with dementia who defines the meaningful purpose.

Lay people

A total of 34 positions were identified within the Supported positioning theme. Positive positions accounted for 15% (5), neutral positions 56% (19) and negative positions 29% (10).

Positive positioning occurs when Beryl is acknowledged as having and achieving a meaningful purpose:

> *LPB:*
> *She doesn't sound too bad, you know, considering she's got a life..You know she's got a life and erm..She's obviously got telephones and things and..* (Supported + 2nd)

There are no suggestions that Beryl cannot identify her own requirements for meaningful purpose although external factors have impacted on her ability to fulfil her objectives:

> *LPA:*
> *So, if the bus went everyday, she'd probably go everyday.* (Supported +)

LPC:
Or more often, isn't it? (Supported + Confirm)

The reduced bus service is acknowledged as a barrier for Beryl to achieve her purpose but similar to how the same situation was framed in the *Able* theme, Beryl is positioned as being able to support herself if provided with the correct tools.

The bus service framed several passages of discourse, which were difficult to analyse. Whilst the discourse was rooted in the context of the bus service, the positions offered varied in their theming and value. During analysis, finding consistency when allocating themes was difficult resulting in several analysed transcripts with opposing results. This discourse was typically allocated to Able or Supported positions but the alignment between the attempts at analysis was erratic. The identification of Dementia Unseen positions within the same discourse complicated the analysis further. To address these complex sections of discourse, they were removed from the main transcript and further attempts were made to arrive at a consistent analysis. However, each further analysis also created more results to synthesise, meaning that rather than providing clarity, this extra analysis created greater uncertainty. I discussed the messiness of this analysis, alongside similar complex passages, with the supervisory team and suggested using the process of the positioning analysis model (see figure 30) as a means to determine what position was not being allocated, rather than just what was allocated. Whilst working backwards with the analysis model was a good mechanism to ensure the positions and values could be justified and traced back to their origin, using this method to clarify these more unclear positions also supported the allocation of discourse to themes. For the bus service discourse, the proposed neutral indicators (see Table 13) were taken to their final point on the positioning value indicators table (see Table 15) and analysed using the positive, negative and neutral indicators. By taking these complex sections of discourse it was possible to regain the consistency of analysis that was being achieved elsewhere.

Attendance at the day centre is viewed as a potential solution to provide Beryl with purposeful activity:

LPA:
And they could have s, s, sing-a-longs and tea and coffee. (Supported = Confirm)

LPB:
Yeh and bingo or anything, whatever…and maybe even a craft, I don't know. (Supported = Confirm)

This discourse achieves neutral positioning within the *Purpose* sub-theme as the participants suggest probable activities that would be offered to Beryl if she did attend the centre. The positive value for the sub-theme is not achieved as the activities are not considered in the context of their individual value to Beryl. There is an assumption in identifying the activities that they would automatically be appropriate for Beryl, as a person living with dementia, to feel socially fulfilled. The application of this position to others is also suggested:

> *LPD:*
> *Yeah. Everybody would benefit from that.* (Supported = Confirm)

> *LPE:*
> *Everybody thinks, she, she'll meet more people and other people. Them people would be after her, they'd looking out for her.* (Supported = Confirm)

The term *'everybody'* actually refers to other people living with dementia rather than the global *'everybody'*. The neutral position is created as the discourse suggests that all people living with dementia require meaningful purpose although there are negative connotations through the intimation that all people living with dementia share the same purpose. This position is aligned to the *Dementia Unseen* theme as the decision is based on the diagnosis rather than the person.

Negative positioning occurs when the group discuss denying Beryl her current activities that may fulfil her need for meaningful purpose:

> *LPE:*
> *There is a small local shop half a mile away, although is down a..a definitely don't think she should be doing that.* (Supported -)

> *LPD:*
> *No, she shouldn't.* (Supported – Confirm)

The suggestion that she should not engage in this activity is related to their concerns that continuing to walk to the local shop creates a probable risk for Beryl. No considerations are included to suggest that the activity may have significant value for Beryl.

Safety concerns are used to allude that Beryl will not be able to continue living at home, with home appliances used dangerously rather than purposefully:

> *LPA:*
> *Well, I think she'll deteriorate and go worse and worse…put her knickers in the microwave like this lady used to…that I used to…* (Supported -)

A negatively valued Encourage position is create as LPB suggests that Beryl will be unable to use the microwave for its correct purpose and should be prevented from using the appliance.

Family members/carers

A total of 14 positions were identified within the Supported positioning theme. Positive positions accounted for 7% (1), neutral positions 64% (9) and negative positions 29% (4).

A neutral position evolves for the participant's relative with dementia when the discourse identifies an unmet need for stimulation:

> *FA:*
>
> *What I think with (name's) father with dementia and he went into a home and you don't get as much attention in the home. He wasn't having any stimulation at all. He was in the corner.* (Supported =)

The negative implication that FA's father-in-law was *'in the corner'* without stimulation can be directly aligned with Sue's demand, during the AI outcome, that people recognise that people living with dementia's need for active purpose should be understood by others:

> *They need to understand that just because we've got dementia, doesn't mean we are going to go and sit in a corner. We're active. We try our best to do things and we don't like being told 'no', like a two-year old.* (Sue)

Neutral positioning continues as the group discuss their own experiences of observing family members in care homes when there was a lack of stimulation for the person living with dementia and the damage that was caused by this absence:

> *FC:*
>
> *Yes, visual reminders which would help them to remember what to do because (points to A), you were saying that, erm, there was somebody that went into a home and they just went into themselves because they weren't having any. He wasn't having any stimulation there, as such, so it is difficult but I still think if they can, it's important that they can be in their Cynefin.* (Supported =)

Despite the reservations expressed regarding the potential barriers to meaningful activities, which the group had observed in care homes, this did not appear to influence their decision regarding whether Beryl should attend a day centre:

> *R:*
>
> *Do you think that Beryl would benefit from going to a day centre?*
>
> *FC:*
>
> *Definitely.* (Supported -)

FB:
Yeah. In regards of the activities and the socialising and talking. (Supported – Confirm)

FA:
Stimulation. (Supported – Confirm)

Although the recommendation that Beryl attends a day centre suggests a belief that Beryl requires activity there were no further considerations regarding whether Beryl would find attendance at the day centre purposeful. The decision for Beryl to attend the day centre was predominantly based on concerns regarding her safety, although the group did suggest that there are potential social benefits. The possibility of finding meaningful purpose outside of a day centre was not discussed with the suitability of the day centre for Beryl unquestioned (*'Definitely'*).

The purpose to attend the day centre was expanded further:

FC:
And get them to move as well. (Supported = Confirm)

The group agreed that activities that included exercise would be physically beneficial despite earlier denying Beryl the purpose of walking to her local shop.

6.2.4 Beryl: Dementia Unseen

Healthcare workers

A total of 6 positions were identified within the Dementia Unseen positioning theme. Positive positions accounted for 17% (1), neutral positions 66% (4) and negative positions 17% (1).

A relative dearth of *Dementia Unseen* positions were created in the discourse of the group. Positions were often attached to the experience of working with people living with dementia which tended to focus on clinical care and activity, perhaps influencing the statistically greater number of positions in the *Able* and *Supported* themes observed in the healthcare worker's discourse.

The identification of potential symptoms that participants had observed in other people living with dementia were used to neutrally position Beryl within the sub-theme *No dementia*:

HWE:
(reads) What do you think might happen to Beryl if she does not receive the help you have suggested?

HWF:
Isolation, depression, withdrawal. (Dementia unseen =)

HWE:
Erm..Deteriorate. How's about an assessment (inaudible) (Dementia unseen = Confirm)

Equally, observations regarding potential benefits of technology for people living with dementia were discussed as plain observations rather than as a means to consider the theme in either a negative or positive context:

HWF:
No, but they wear them on their wrist like a watch. (Dementia unseen =)

HWB:
Do they? (Dementia unseen = Confirm)

The pronoun *'they'* has significant potential to negatively position people living with dementia as it can indicate that all people living with dementia are the same or are different to other people. In the context of this discourse the pronoun is used without this negative connotation as the description of *'they'* is used to describe people who use wrist alarms, rather than as a descriptor for all people living with dementia.

One positive position is observed when HWF acknowledges the requirement to see beyond the individual's dementia when considering the subjects the healthcare workers discuss in the care home with people living with dementia:

HWF:
You personalise it to the person. (Dementia unseen +)

The positive position belongs in the *Doesn't matter* sub-theme as the individual's interest are used to influence the conversational subject rather than the dementia diagnosis.

Lay people

A total of 24 positions were identified within the Dementia Unseen positioning theme. Positive positions accounted for 4% (1), neutral positions 46% (11) and negative positions 50% (12).

Potential behaviours are used to negatively position Beryl within the *No dementia* sub-theme:

LPC:
And so what do you think might happen to Beryl if she does not receive the help you have suggested? She could wander as you say… (Dementia unseen – 2nd)

LPB:
Wander off. (Dementia unseen – Confirm)

> *LPC:*
> *She could wander and not know where she was.* (Dementia unseen – Confirm)

> *LPA:*
> *Don't know day or night you see. That was what was happening to this lady and then the other was setting things on fire (inaudible).* (Dementia unseen – Confirm)

The importance of the sub-theme is illustrated as the negative assumptions about Beryl's potential progression and apparent behaviours aligned to this deterioration eventually lead to conversations regarding risk, which influenced further negative positioning in the *Able* and *Supported* themes. Having observed another person living with dementia who was disorientated to time, informs the LPB's allocated position that Beryl must also experience this symptom.

Beyond behavioural aspects, the experience of one person living with dementia encapsulating the experience of all people living with dementia is intimated further:

> *LPB:*
> *I mean..and I always think..well, I don't know about dementia..I always think they get scared.* (Dementia unseen =)

The neutral *Doesn't matter* position is achieved as the experience of being *'scared'* is judged as a potential symptom, which is not used to negatively assess the person living with dementia.

Perceived negative consequences increase the likelihood of negative positioning as experiences of other people living with dementia are applied to Beryl:

> *LPA:*
> *Another lady I knew, she stuck an electric kettle on the gas.* (Dementia unseen –)

The application of these personal experiences to Beryl's situation are countered when the group consider the evidence within the case study itself, creating neutral positions when no assumptions are made.

> *LPC:*
> *But it doesn't say she goes wandering anyway but erm.. (*Dementia unseen = 2nd)

> *LPB:*
> *Yeah, it depends how bad her dementia is.* (Dementia unseen = Confirm)

The group acknowledge that although Beryl does have dementia, they are not aware what stage she is currently experiencing. This position creates a tacit self-position for the speaker who does not deliberately state how they position themselves but does position themself as an individual who will not position others, including people living with dementia, without access to greater evidence. The neutral *Doesn't matter* position is created for the person living with dementia as the speaker is aware that the person living with dementia has dementia but is not prepared to use this to influence their positioning until they are aware of how their diagnosis of dementia affects them. The positive position is not achieved as the discourse still implies that once this information is provided, the speaker will utilise this to allocate a new position for the person living with dementia rather than seeing beyond the diagnosis. This tacit self-position, which reinforces the neutral position for Beryl, is spoken by other members of the lay person group:

> *LPF:*
> *It depends also, do you think it depends on what stage of dementia she is at?* (Dementia unseen =)

Positive positioning within the No dementia sub-theme is achieved when there are no observable differences in the roles provided to people without dementia compared to people living with dementia:

> *LPC:*
> *Yeah, the thing is if, if the bus is only twice a day, it's gonna be the same for the friend, as it is for her. So unless the friend has got transport, what can you do?* (Dementia unseen +)

The diagnosis is unimportant when assessing the impact of the bus service reduction. The positive *Dementia Unseen* position is observed when the impact of the service change is regarded as identical for Beryl as it is for her friend without dementia.

Family members/carers

A total of 16 positions were identified within the Dementia Unseen positioning theme. Positive positions accounted for 6% (1), neutral positions 31% (5) and negative positions 63% (10).

Tacit self-positioning observed in the lay people group is also observed in this group, creating the same neutral position for Beryl:

> *FB:*
> *It depends on the level were the dementia is and it was difficult to say from that (points at paper).* (Dementia unseen =)

The majority of positions within the Dementia Unseen theme in this group had a negative value. Discourse was driven by the experiences of the participants and this was used to inform their subsequent positioning of Beryl and other people living with dementia:

> *FB:*
> *Their sense of time goes, doesn't it? But, not every time..* (Dementia unseen -)

> *FC:*
> *But it also says it's important for them to go out, doesn't it? Not just (Inaudible) well-being and other things. The fact that the bus service has decreased, she's far from the town and she lives up a steep hill. All of this are against her really. Aren't they?* (Dementia unseen – Confirm)

Using the pronouns 'their' and 'them' in this instance positions the person living with dementia as different to other people and places their diagnosis as the indicator for positioning. Although the considerations of FC are sympathetic towards Beryl, the conclusion that she is vulnerable is based on her diagnosis rather than supporting evidence from the case study. *'It's important for them to go out'* suggests that people living with dementia are somehow different to other people and that the need to '*go out*' is different for people living with dementia compared to other members of society who potentially do not have this requirement.

The positioning of all people living with dementia is intimated further:

> *FC:*
> *They can get quite agitated if they're on their own, erm, can't they?* (Dementia unseen -)

> *FB:*
> *Yeah.* (Dementia unseen – Confirm)

Agitation related to isolation is regarded as another product of dementia rather than a by-product of isolation itself.

Discussing the possibility of Beryl attending the day centre, the group suggest that this will not be sufficient due to the symptoms of her dementia. A negative *Doesn't matter* position is created as the knowledge of Beryl's diagnosis is used to state how her needs should be addressed:

> *FD:*
> *Because they have to have routine. And it says here, it says day centre here, doesn't it? What about the nights? So, she wouldn't be able to stay and they get up in the night four or five times and the person who's with them, say it's their husband or wife, erm, there with them, it's exhausting. Just like what happened to (name). He died in his bed.* (Dementia unseen – 2nd)

The proposal that Beryl '*wouldn't be able to stay*' in her bungalow is informed by the family member/carers experience of dementia when their own relative has required 24 hour care, which is used as a mechanism to position all other people living with dementia. The negative *Doesn't matter* position is reinforced as the consequences of Beryl remaining at home are aligned to an actual incident when a carer's death is attributed to the stress of caring for their relative with dementia. Beryl's dementia is regarded as limiting her options for safe social living and as potentially life threatening to others who support her.

FC's experience with a relative with dementia was shared during the case study:

> *FC:*
> *But it is difficult accepting that the person that you've known forever has changed, isn't it?* (Dementia unseen – 2nd)

Although FC's own position is experientially valid for her, the Balancing Framework aligns this observation to negative *No dementia* positioning. The example illustrates the conflict in achieving desirable positioning for one group and accepting the lived experiences of others who oppose these positions.

6.3 Sally

The development and content of the case study 'Sally' is detailed in section 2.4.2.

6.3.1 Sally: Belonging

Healthcare workers

A total of 26 positions were identified within the Belonging positioning theme. Positive positions accounted for 19% (5), neutral positions 27% (7) and negative positions 54% (14).

A negative *No blame* position is allocated to Sally's husband rather than Sally herself during discussions regarding whether the two of them should continue living together:

> HW*E:*
> *Well I think personally, Sally's struggling. I think her husband might be quite far in advance because, like, she's give up her role as a club treasurer..erm..* (Belonging -)
>
> *HWF:*
> *She's made all the sacrifices hasn't she?* (Belonging – Confirm)

Sally's husband is positioned as the cause of her difficulties with the group insinuating that it is his dementia that has stopped Sally from acting as a club treasurer for the bowling team. Sally is positioned as a selfless carer, abandoning her own assumed desires due to another person living with dementia. However, the positioning of the husband dominates the narrative, informing the negatively valued position.

A statement concerning the relationship between Sally and her husband and their ongoing needs provides a neutral position for both of them:

> *HWB:*
> *I suppose you could, you could get like a place where they could take them and play bowls together.* (Belonging =)

The proposal for the couple is to attend a day centre where they will be able to play bowls and fits into the larger discourse that they will meet other people similar to them in the centre. A neutral *Respect* position is created through the acceptance that they should be with each other but this does not achieve a positive value as there is no consideration whether their decision to stop bowling should be investigated or respected. The activity is regarded as something they must engage with. The larger discourse that suggests they should be with other people like them leans towards a positive value but remains neutral as the definition of similar people is limited to other people living with dementia.

Some members of the group share an assumption that Sally's husband has declined further in his dementia compared to Sally:

> *HWE:*
> *But does she want to be, just be closer to home because her husband's so bad?* (Belonging –*)*
>
> *HWF:*
> *And how do you know that?*
>
> *HWC:*
> *You're making a lot of assumptions.* (Belonging + 2nd)
>
> *HWD:*
> *It doesn't say..* (Belonging + Confirm)

Sally's husband is negatively positioned within both sub-themes as he is blamed for Sally's assumed reluctance to leave the house due to her caring role whilst the level of respect applied to Sally is different to that applied to her husband. Positive positioning occurs through statements, which in isolation would have no positional value. HWC and HWD both challenge the narrative that has developed around Sally's husband to suggest that without factual evidence he cannot be blamed or disrespected.

The positioning of people living with dementia now includes the people living with dementia in the AI outcome video:

> *HWC:*
> *Depends on how far advanced her dementia is because it might be a case of their like the people in the videos.* (Belonging +)

Although the language is similar, this discourse diverges from the neutral *Dementia Unseen* position when assumptions about the people living with dementia are regulated by considering the stage of the person's dementia. The position is allocated to the people living with dementia from the AI outcome and meets the positive requirements for *Respect,* as the AI participants are regarded as equally deserving the respect of others. The dialogue also considers how the respect shown to those people living with dementia could also be applied to Sally.

Lay people

A total of 33 positions were identified within the Belonging positioning theme. Positive positions accounted for 73% (24), neutral positions 3% (1) and negative positions 24% (8).

The *Respect* sub-theme is positively achieved as Sally and her husband are located within their society:

> *LPF:*
> *So, obviously they're still part of the community, aren't they?* (Belonging + 2nd)

The position is strengthened through the language, particularly the word *'obviously'*. By suggesting that Sally and her husband should *'obviously'* be considered as part of the community, HWF also presents a challenge to any potential second order positioning, with adverse repositioning having to be justified against the 'obvious'. The discourse allocates Sally and her husband with the same degree of respect of others in their community.

The equality between Sally and her husband is also addressed:

> *LPB:*
> *It's all..it said..what d'you think would help Sally? Well, surely it's her husband and Sally?* (Belonging +)

The case study is repositioned to assess the situation for Sally and her husband, positioning both as equally important when decisions are being made about potential care needs.

Whilst discussing their proposed attendance at the day centre, the respect previously allocated to their relationship is undermined:

> *LPA:*
> *The two of them. And maybe they could go on separate days because then, if they went together they might just stick together. Where, as if they went separate days, they'd interact with other people.* (Belonging – 2nd)

Whilst positive positioning was achieved by discourse that respected their relationship, a negative position is created when the relationship is regarded as potentially harmful or limiting. The group discuss separating the couple to encourage their social behaviour and therefore create new alliances:

> *LPB:*
> *They're gonna be together and not making new friends.* (Belonging – Confirm)
> *LPA:*
> *Where as separately they'd interact, maybe with other people. I think they would. There you are. Either, Sally would..* (Belonging – Confirm)

Being together is considered detrimental to their social life as they are deemed unlikely to interact with potential new friends if they continue to interact with each other. The negative *Respect* sub-theme is achieved as new relationships are positioned as having greater meaning than their existing partnership.

This negative position is demonstrated again when the previously positive position regarding the care needs of Sally and her husband is not acknowledged:

> *LPC:*
> *Well, well, well. I think really it's not that, I think it's the, the thing is, it's, it's, it's about, it's about Sally and not her husband, basically.* (Belonging -)

Sally's husband is not regarded with the same respect as Sally, with HWC suggesting that decisions should not be considered on the basis of his needs or what may be suitable for both of them.

The separation of Sally and her husband is not advocated by all the participants:

> *LPC:*
> *But also they could be a support for each other because they know, they both know, they might not have told anybody else what's wrong with them.* (Belonging + 2nd)
>
> *LPD:*
> *Well, that's true, yeah, yeah.* (Belonging + Confirm)

The relationship is implied to be a considerable source of existing support for Sally and her husband. By recognising and respecting the existing relationship between the couple, positive positioning is achieved as the worth of their own support is appreciated.

Family members/carers

A total of 16 positions were identified within the Belonging positioning theme. Positive positions accounted for 56% (9), neutral positions 0% (0) and negative positions 44% (7).

A negative *No blame* position is instigated when the scenario is revealed to involve a couple who both have a dementia diagnosis:

> *FD:*
> *That's double trouble.* (Belonging -)

People living with dementia are positioned individually as '*trouble*' and therefore can be blamed for any difficulties that occur due to their diagnosis. The situation in the case study is positioned as having been made worse due to the involvement of two people living with dementia, magnifying the situation two-fold.

The negative *No blame* position is repeated when the group discuss the changes to Sally's driving activities:

> *FC:*
> *And it feels, erm, in here as well, as if she's on her way as making herself more lonely as well, through the fact she's starting to lose confidence in her driving and pulled herself out of the role which is quite responsible, in the bowls. Is she starting to pull herself out of, away from things which means she'll have less stimulation and less company and wanting to prevent that if possible. I don't know how but if she's isolating herself, it's going to be harder to support her.* (Belonging -)

Sally's decision to stop driving longer distances, as well as the decision to stop acting as club treasurer for the bowling club are regarded as actions that Sally has chosen, which will cause her to experience isolation and loneliness. Her actions are viewed as having negative consequences, with no consideration of positive potential, which she has solely instigated.

The *Respect* sub-theme is addressed positively through discussions about the relationship between Sally and her husband:

> *FA:*
> *It's definitely better for them to be together because they're used to being together.* (Belonging +)

The value of their relationship is respected as well as the requirement to understand that their '*being together*' is as equally important now as it was in their pre-dementia experiences.

Respecting the experiences of people living with dementia is expanded to positively position all people living with dementia, beyond Sally and her husband, when considering their needs and the actions of those interacting with them:

> *FC:*
> *I think the only thing you can do is treat them as individuals and if one wants and another wants empathy, well you've just got to go with.* (Belonging +)

By listening and accepting the reality of the person living with dementia, the positioner provides the respect that the people living with dementia in the AI outcome video demanded.

Similar positioning is observed again with direct citation to the AI outcome:

> *FC:*
> *Yes, but, erm, close friends felt, find it really difficult to accept, erm, as they said in the video, it's the people who are closer. Friends probably find it difficult to accept and it would be interesting to know if the members of the church or the bowls, did know so that they could offer support. Because those networks are really important but they've pulled themselves out of one of those networks, the bowls, which is then and that, that first says 'when we say no, we mean no'. We're not supposed to then, maybe encourage them to go back to play bowls. That would feel natural to us.* (Belonging +)

HWC acknowledges the positivity of Sally's networks but also challenges some of the group's suggestions that Sally and her husband must continue to engage with all of these networks. The decision to disengage with previous activities is not regarded as an issue to be addressed but a decision that should be respected by others. There is the acknowledgement that the other person may find this difficult with the promotion of the activities '*natural to us*'. However, the direct quote taken from the AI outcome (*'when we say no, we mean no'*) is used to prioritise the decision of the person living with dementia over the family members desire to promote activity.

6.3.2 Sally: Able

Healthcare workers

A total of 54 positions were identified within the Able positioning theme. Positive positions accounted for 24% (13), neutral positions 46% (25) and negative positions 30% (16).

A positive *Capable* position is achieved whilst discussing the couple's requirement for external help:

> *HWA:*
> *D'you know what I mean? They must not have..asked for help.* (Able + Confirm)

> *HWB:*
> *'Cause they might be caring for each other.* (Able + Confirm)

Sally's current lack of external support is considered a choice that the couple have made as they have not asked for any assistance. By not asking for this assistance it is assumed that the couple support each other and therefore their continuing abilities are also assumed.

Sally's insight into her condition is used to positively position her within the same sub-theme when the group consider her decision to stop driving long distances:

> *HWD:*
> *She knows though, that, she's d..She knows that her d..That she's a declining..so I don't think her dementia's that far if she knows..you know what I mean?* (Able + 2nd)
>
> *HWB:*
> *Yeah, 'cause if she knows. If she can feel it in herself that she's like declining then..does that make sense?* (Able + Confirm)

The discourse suggests that Sally has deteriorated due to her dementia but retains the ability to recognise her decline and make sound decisions to maintain her safety. Therefore, although her driving ability may have declined she remains positively *Capable* as she retains the competence to assess risk and adjust her actions accordingly.

A similar position is presented by HWF, who suggests that Sally's change in driving behaviour is a preference rather than an indicator of deterioration. Further considerations result in a negative second order position:

> *HWF:*
> *But it does say that the driving is due to her own preference rather than a decline.* (Able+)
>
> *HWE:*
> *In her driving abilities.*
>
> *HWF:*
> *So would the doctor revoke her licence if..* (Able – 2nd)
>
> *HWE:*
> *Yeah, maybe if she has a review.* (Able – Confirm)

The initial positive perception that Sally has chosen not to drive long distances is challenged by the suggestion that if she had a medical review it would be probable that her driving license would be rescinded. This negative *Superior* position damages the earlier positive statement through the assumption that Sally's personal action only remains a 'preference' until someone else with greater ability makes this decision for her. In this instance the decision will not only limit the distances Sally drives but abolish all driving behaviour.

Inferences regarding a lack of insight, for both Sally and her husband, create a negative *Capable* position:

> *HWF:*
> *She said she's given up driving from her own preference but perhaps that's become because she can't do it.* (Able-)

On revisiting Sally's driving preference the discourse is altered to include '*she said*' prior to stating her decision. This allows doubt to be cast on the information that Sally has altered her driving behaviour due to a preference, suggesting that this is how Sally wants the situation to be positioned rather than the information being factually accurate. The discourse also aligns to a negative *Superior* position as their lack of external support indicates the need for a review by a capable person rather than a valid decision made by Sally and her husband.

The suggestion that Sally is not driving long distances due to a deterioration rather than a personal preference is extended as the group discuss the perceived reasons why she should not be driving:

> *HWB:*
> *She could get lost, or she (inaudible) get lost.* (Able -)
>
> *HWC:*
> *Yeah, she might not remember her way back like.* (Able- Confirm)

The proposed lack of ability of the couple is enlarged to include further difficulties impacting on their activities of daily living and social situation:

> *HWD:*
> *They wouldn't know how to use a phone anymore to get the help. They've got no family. They could be stuck in. Forget how to get out.* (Able -)
>
> *HWC:*
> *Personal care.* (Able - Confirm)
>
> *HWE:*
> *And looking after themselves.* (Able - Confirm)

The discourse suggests that there is a significant deterioration in the couple's abilities leading to a general suggestion that they need external support '*looking after themselves'*.

Whilst these latter statements are generally based on assumptions, information form the case study is used to justify negative *Capable* positioning:

> *HWE:*
> *Yeah, but if she's given up her role as a club treasurer then she shouldn't be driving, I don't think then.* (Able – 2nd)
>
> *HWG:*
> *No, no, she shouldn't be driving.* (Able – Confirm)

Sally's decision to step down as the club treasurer of the bowling club is regarded as a consequence of her declining abilities, which is then used to inform the decision that she should not be driving. A perceived lack of ability in one area is used to position Sally has incapable in other unrelated areas of her life.

Lay people

A total of 31 positions were identified within the Able positioning theme. Positive positions accounted for 48% (15), neutral positions 29% (9) and negative positions 23% (7).

A neutral position is achieved through statements that are generally non-comital to the requirement of external support:

> *LPA:*
> *Oh, yes but I think they should have a little bit of something from the health or social services. Even if it's just a , somebody coming in every month or so to see how they are because they've got no support off either the health or social services, have they? So, they need something off them, don't they? But while they can live together, carry on and the rest is fine.* (Able = 2nd)

In this example, LPA suggests that supervision could be helpful because otherwise they do not have any support. It is also suggested that Sally and her husband should continue in their current state. The neutral position is achieved as LPA does not suggest that the couple are lacking ability but neither does the call for 'support' suggest that their ability should be trusted.

Sally's ongoing abilities are upheld at the expense of her husband:

> *LPB:*
> *Sally seems to be doing everything?* (Able =)

The neutral position is indicated overall when considering the general positioning of people living with dementia although for Sally, the statement could suggest a positive *Superior* position as she is regarded as having greater abilities compared to her husband. Equally, her husband is positioned negatively through the same analysis. However, as the comparison is between the abilities of two people living with dementia, rather than between a person living with dementia and a person without dementia, this does not meet the requirements of positive positioning in the AI outcome, creating a neutral position.

A positive second order position is observed during a disagreement regarding whether the couple should be home without support:

> *LPD:*
>
> *We have to say, don't we, straight away that no, we don't think they should be on their own? There should be some support, shouldn't there?* (Able -)
>
> *LPE:*
>
> *No, They'll be fine. At least, no, I still don't think they need it because (gestures towards TV) they could be young couple and the, there's, people we just looked at.* (Able + 2nd)

The AI outcome is used as evidence to support the positive *Capable* position. He positive position disregards any potential barriers to the couple remaining at home through the statement '*they'll be fine*', suggesting that objections raised about their current living situation are concerns for others which are unwarranted.

LPE continues to express positive *Capable* positions for the couple:

> *LPE:*
>
> *So, I don't see how, at this stage in her life, that's how I see it. I don't think they need, yeah, they've got the means to phone themselves and as soon as the husband deteriorated or she did, then I reckon one of them would do it. Because they know that they've both got dementia so, I, I really personally do think it's safe for Sally and her husband to be living together without support. I think they're fine together, personally, fine together without support. But if they deteriorate, which one of them..help themselves.* (Able +)

The potential decline in the person living with dementia's abilities is not denied whilst considering Sally's situation whilst a positive Able position is retained as the couple are self-supporting. If the abilities of one person decrease, the other will have the capability and capacity to react appropriately. The statement '*they know that they've both got dementia'* is used to enhance the positive position, rather than use dementia as a negative indicator, the knowledge of their diagnosis is positioned as a strength that increases their capability to recognise when they may need external support.

The positive perception of their abilities to maintain their current lifestyle is considered self-evident:

> *LPC:*
> *Well, they obviously don't need any help, do they, in the house to look after themselves or whatever? But they, yeah, I think they do need.. (*Able +)

Using the word '*obviously*' empowers the statement to challenge any proposed negativity to justify an attempted repositioning.

Sally's continued abilities are also used to justify why there is no current benefit for her to attend a day centre:

> *LPE:*
> *What would Sally do there? There's no nee..At the moment I don't think they need any help with, they're perfectly capable. They've never had any children and there is (Able +) no other family members in the area. They both regularly attend church. They're just living with dementia aren't they? They're keeping their independence until such time, this is how, that's my opinion anyway, going by that video. They don't want anybody interfering, you know, well obviously, I mean that lady, you know.* (Belonging +)

The statement 'they're perfectly capable' aligns directly to the relevant sub-theme whilst examples of their ability are used to clarify the statement. Dementia is not ignored or belittled, with LPE stating, '*They're just living with dementia aren't they?'* Although the couple may both have dementia, the diagnosis alone does not indicate their current abilities as they continue to live independently. External support is also repositioned from being necessary to '*interfering*', strengthening the positive *Capable* position further through the positioning of others.

A positive *Capable* position is inferred in Sally's driving ability:

> *LPE:*
> *And if she's young, ish, still, well she's still driving.* (Able +) *I think, whereas I felt that Beryl, obviously, was a lot older.*

The positive position is created through the acknowledgement of Sally's driving ability. Sally's age is suggested as a possible indicator for positive positioning with LPE suggesting that Beryl would not receive the same positioning as she was regarded as older. There are no age details in the case study although this statement is indicative of further bias, outside of dementia, as influencers of positive and negative positioning of others.

Family members/carers

A total of 23 positions were identified within the Able positioning theme. Positive positions accounted for 30% (7), neutral positions 0% (0) and negative positions 70% (16).

The initial discussion following the reading of the case study presented a positive *Capable* position, which was immediately challenged by a negative second order:

> *FB:*
> *She's safe to be at home.* (Able +)
>
> *FC:*
> *But they've both got dementia.* (Able – 2nd)

The initial statement provides a clear statement of belief, albeit without evidence. The second order uses the couple's diagnosis of dementia to challenge the statement, suggesting that they cannot be safe at home if dementia is present.

The complexity of data analysis and ensuring consistency across all the narratives is well illustrated in this example. Whilst reviewing the results across the first attempts to analyse the data over several transcripts, FC's discourse: 'But they've both got dementia' was consistently analysed, in three of four analysed transcripts, as a negative position within the Dementia Unseen theme. Taking the position as an isolated piece of discourse, this result is consistent with the theming and value indicated in the positioning value indicators table (see Table 15). However, one transcript had allocated a negative Able theme to this discourse. I was inclined to accept the Dementia Unseen position and take this to the supervisory team. However, the single allocation of the Able theme prompted me to embrace the wider storyline of the discourse and through this, it was evident that this position was more closely aligned to the Capable theme. This led to a difficult period of analysis as I returned to previously analysed text to ensure that this isolated analysis had not occurred elsewhere. I had also reported to the supervisory team that analysis was moving swiftly but this incident led to further analysis of the healthcare worker and lay people groups, slowing the progress of the thesis considerably. The supervisory team was very important here, not only in support of the analysis but also their reassurance that these issues were part of the research journey, were moments of learning rather than failure and by revisiting the previous analysis, strengthened its overall rigor.

External support is regarded as necessary but is not defined:

> *FC:*
> *More support.* (Able -)

FA:

Maybe they've had the phone number but would they remember they've got the phone number. (Able – Confirm)

FC:

Exactly. (Able – Confirm)

FA:

Maybe they're deteriorating without realising. (Able – Confirm)

FC:

Exactly. (Able – Confirm)

FA:

You can't just give a phone number to people who've got dementia. (Able – Confirm)

FB:

There's no objectivity there, is there? And both are in the same situation. (Able – Confirm)

The couple are proposed to lack insight and therefore unable to use a phone number to ask for support, or recognise when support may be needed. The phone number is dismissed as a means of support, as people living with dementia are regarded as unable to use this. Both Sally and her husband are considered to have the same abilities and therefore both lack the capability to ask for help.

This lack of insight, coupled with a potential lack of practical ability is considered when driving is discussed:

FA:

And driving is dangerous. (Able –)

FB:

Yes, dangerous. (Able – Confirm)

Sally's perceived lack of ability places herself and others at risk. Her decision to continue driving is considered unsafe as she lacks the ability to perform the task adequately.

The negative concept of Sally's driving is dismissed in further communications when her decision is regarded as sound:

FC:

I did that, I did that yesterday. My car broke down. But it was quite interesting to hear that, erm, she decided rather than been declined. So, that's interesting in, in terms of the case study. The case study objective saying that no, her driving ability hasn't deteriorated. (Able + 2nd)

FC indicates a willingness to positively position Sally following her decision as there appears to be evidence to support it. The belief that the case study agrees that Sally's driving ability is unchanged allows FC to agree with Sally's preference, creating a positive *Capable* position. FC considers the validity of the decision over a presumed decline '*quite interesting*', suggesting that without supporting evidence the positive position may not have been achieved.

The acceptance of Sally's preferences, indicating a belief in her ongoing ability to make decisions is more clearly observed in a discussion about bowls:

> *FD:*
> *Yes, yes. It doesn't suit everybody. It depends what type of person she is. If she's* (Dementia unseen +) *pulled herself out of the bowls club thinking she can't be a treasurer, she's quite self sufficient.* (Able +)

Sally's decision to stop bowling is accepted and used as an indicator that she remains '*self sufficient'.* The decision to stop bowling is considered a consequence of her being unable to fulfil the role of club treasurer. This latter decline in her abilities is not used to negatively position Sally within the theme, as the insight required for this decision is presented as a positive indicator of her abilities.

6.3.3 Sally: Supported

Healthcare workers

A total of 20 positions were identified within the Supported positioning theme. Positive positions accounted for 35% (7), neutral positions 40% (8) and negative positions 25% (5).

The value of meaningful activity for Sally is considered:

> *HWF:*
> *We wondered why she'd actually stopped playing, whether it was just because she gave up her role as treasurer and then she completely stopped..so we think she's lost her self worth because she felt empowered as a treasurer and then once that, once she gave that up she felt she didn't have a place anywhere. So, we think she's lost her confidence and that..so..* (Supported =)

The discussion has a neutral value as potential detriments are perceived, based on the loss of Sally's role as club treasurer without considering potential activities available.

Neutral positioning is observed again as the value of her club treasurer role is considered, although again this is positioned as a loss. Although the purpose of the role is appreciated, which potentially could have positive consequences, the emphasis on lost purpose denies the positive position:

> *HWE:*
> *I think if she thinks she can't be a treasurer she can't do it, she can't just play anymore.* (Able -)
> *Perhaps maybe being a treasurer gave her a sense of worth like that woman was talking about on the video.* (Supported = 2nd)

Neutral positioning continues when a suggestion is made to transport Sally and her husband to play bowls:

> *HWD:*
> *So, somebody could take her and her husband to bowls..it's far away, then they still got what they want to do then, rather than not got to bowls.* (Supported = 2nd)

The potential positive *Encourage* position created by the suggestion that someone should support the couple to engage in a meaningful activity is reduced to a neutral position as the suggestion is based on the participant's beliefs regarding what is meaningful. Sally's decision to stop bowling is not used to inform the decision.

Negative positioning is created through misinformation:

> *HWD:*
> *Don't go church anymore do they?* (Supported -)

A negative *Encourage* position is created as HWD wrongly suggests that the couple do not attend church, despite contrary evidence in the case study. Although, this statement has presumably surfaced through a misreading of the case study text it does presume that Sally is unable to fulfil her meaningful purpose. No other group members attempt a second order position to rectify the misinformed position, allowing the negative position to remain unchallenged.

The correct information is used to positively position the couple in a later conversation:

> *HWF:*
> *They're both still going to church though.* (Supported + 2nd)

An activity to provide meaningful purpose for Sally creates a negative position:

> *HWG:*
> *'Cause where it says what would Sally do there? Do you know like these days they have all that technology, like the VRs and stuff, If they do revoke her licence and she missed the driving they could do stuff like that in day centres.* (Supported – 2nd)

The day centre is viewed as the potential source of meaningful activity, with a virtual reality driving experience regarded as purposeful task for Sally. If Sally was to lose her license, the experience of driving could be replicated using this technology. No consideration is given to the purpose of Sally's driving beyond the act of driving. The suggestion that Sally should drive without a purposeful destination indicates a negative position within the *Purpose* sub-theme.

Lay people

A total of 33 positions were identified within the Supported positioning theme. Positive positions accounted for 70% (23), neutral positions 30% (10) and negative positions 0% (0).

The need for purpose is recognised although a neutral position is achieved as the proposed purpose is limited to the day centre and does not consider her current activities:

> *LPB:*
> *I would think, she can't be that bad and I would think if she did go to the day centre she could be helping to, to make the teas and the sandwiches and that to look after people who are worse than her.* (Supported = 2nd)

The discussion considers helping at the day centre as having greater meaning than Sally's current activities. A positive position is created when activities outside of the day centre are considered for Sally as well as possible attendance at the day centre. These activities strengthen the positive position are they are informed by Sally's current activities, including attendance at church:

> *LPC:*
> *They can, they can, they can go to the day centre, erm. They can go into town and then meet people or whatever they, obviously, can go to church. The, there might be church socials that they can go.* (Supported +)

The discrepancy between terminating her role as club treasurer as well as giving up bowling is addressed:

> *LPC:*
> *Well, why did they have to, they didn't have to give up bowls because, just because she, just because she gave up her role as a club treasurer doesn't mean that..stopped, why, why have they stopped?* (Supported + 2nd)

The positive position is created as LPC recognises that Sally and her husband can potentially still engage with an activity if they choose to. Having lost one activity does not negate other potential pursuits.

Further positive positioning is observed as Sally's ability to drive is viewed as a mechanism for her to fulfil her meaningful purpose:

> *LPD:*
> *She drives.*
>
> *LPE:*
> *Yeah. So, she certainly hasn't deteriorated.* (Supported +)
>
> *LPF:*
> *So, that's a form of independence, isn't it?* (Supported + Confirm)

The *Encourage* sub-theme is achieved positively as the group recognises Sally's ability and indicates that the motivation to engage with this ability, supports her independence and therefore Sally's own purpose.

The day centre is disregarded as a potential provider of meaningful purpose as Sally is positively positioned within the *Encourage* sub-theme:

> *LPE:*
> *There's two of them. Do you think that Sally would benefit attending the day centre? No, she can do what she wants. She can carry on as normal, I would say. She goes the church. Regularly attends church and the, the church people, we would wonder where she was and we'd be looking out and that she got support inside there. No, I don't think she'd benefit from a day centre, attending a day centre, 'cause she already goes..* (Supported +)

As Sally continues to engage in her own chosen activities, there is no requirement for her to attend a day centre. The discourse can also be aligned to the *Respect* sub-theme in *Belonging*, as Sally's current activities are not diminished but regarded as being sufficient to fulfil her social needs with no expectation that other people must direct her to further ventures.

The issue of meaningful purpose is addressed positively through further discussions about Sally's current activities:

> *LPB:*
> *I, I think she's got enough, erm, of a life.* (Supported + Confirm)
>
> *LPD:*
> *She could, yeah, she could make use of the other part of her life, couldn't she?*
>
> *LPA:*
> *They drive, they go on journeys and that, yeah.* (Supported + Confirm)

By recognising what Sally is already doing, the group conclude that she is fulfilling her need for meaningful activity. Her capabilities are recognised and are considered '*enough*', fulfilling the requirements of positive positioning within the *Encourage* sub-theme.

Family members/carers

A total of 15 positions were identified within the Supported positioning theme. Positive positions accounted for 93% (14), neutral positions 0% (0) and negative positions 7% (1).

Sally is regarded as having no access to meaningful purpose:

> *FB:*
> *And there's no activity.* (Supported -)

The dismissal of Sally's current activities indicates a negative position, despite the insinuation that having no activity has unfavourable implications for Sally. The positive value of recognising Sally's need for purpose is undercut by the lack of recognition for her actual activities.

External support is considered a viable solution to the proposed lack of activity with a support worker potentially offering Sally the opportunity to engage in a meaningful purpose:

> *FA:*
> *They might. You could ask Sally, 'what would you like to do today?' She might want to go for a walk with her husband or she might want to go on her own, away from her husband, as such.* (Supported + 2nd)

Although the proposal continues to ignore Sally's current activities, a positive *Encourage* position is achieved as the purpose of activity is purported to be defined by Sally rather than the external provider.

Positive positioning is also included in the proposed encouragement of activity:

> *FC:*
> *What would help her then? Like you said, it would be nice to encourage her to go back to the bowls but maybe not in that role. What else would help her?* (Supported +)

Bowling is considered a potential avenue for the achievement of meaningful purpose for Sally. Positive positioning is achieved through the recognition of the activity, Sally's ability to tailor the activity to her desires and the promotion of the activity without imposing this on to Sally.

The option of Sally attending a day centre is disregarded:

> *R:*
> *Do you think Sally, in this situation, would benefit from going to a day centre?*
>
> *FC:*
> *Well, I don't think so. I wouldn't think so.* (Supported +)
>
> *FB:*
> *Yes, that's my feeling about it.* (Supported + Confirm)

Sally is positively positioned as having enough current activities, that she finds meaningful and therefore the introduction of day service at this time lacks purpose.

6.3.4 Sally: Dementia Unseen

Healthcare workers

A total of 28 positions were identified within the Dementia Unseen positioning theme. Positive positions accounted for 29% (8), neutral positions 18% (5) and negative positions 54% (15).

Sally's decision to alter her driving behaviour is not considered to be a consequence of her dementia:

> *HWC:*
> *It's like anyone though, isn't it? If you, if something happens like that you don't want to do it, do you again? So..* (Dementia unseen + 2nd)

A positive *No dementia* position is achieved through the suggestion that an adverse incident may have led to Sally making her decision to stop driving longer distances. The position is created as the decision is not considered different to the potential reaction of a person without dementia.

A positive *Doesn't matter* position is achieved when the group consider whether Sally should continue to drive:

> *HWE:*
> *Well I think like short journeys is fine, erm, because it is all about that positive risk taking. There not, like, we're not to take pity on them, they have still got that like, capacity and capability to do it. We shouldn't treat them any different because they have got a diagnosis so I think that's fine (laughs).* (Dementia unseen +)

I had difficulty in analysing this section of discourse due to the laughter at the end of the sentence. Without the laughter, the discourse travelled easily within the positioning analysis model (see figure 30) to arrive at the positive Dementia Unseen position. The reason for the laughter, however, was unclear although the inflection of the discourse appeared sincere and potentially, the laughter was due to HWE's self-awareness that her final point mirrored the discourse in the AI film so closely. I found it difficult to finalise the positive position, however, due to this laughter. Although, it was not typical of the approach to analysis, I examined the surroundings positions of this discourse to ascertain whether the effect of the laughter had impacted on the positioning by others in the group. As the following positions confirmed a positive position, I had to assess whether my concerns over the laughter were due to my own bias as I viewed the laughter here as inappropriate whilst no one involved in the discourse acknowledged the laughter. When discussing the difficulties of analysing these inflections with the supervisory team, we returned to the subject of consistency during the analysis. Therefore, the final positive position of Dementia Unseen was agreed as the laughter itself created no position within the Balancing Framework whilst the discourse itself was consistently positive.

HWE draws on the AI outcome, with particular reference to Pauline's statement:

> *We don't want your pity, so please, just treat us with respect.* (Pauline)

The decision whether Sally should drive, should not be based on the knowledge that she has a diagnosis of dementia. It should be based on her ability to drive safely. The decision should not be influenced by her diagnosis, whether this has a preferential or detrimental outcome for Sally.

Dementia is used as an indicator for why Sally has stopped driving longer distances:

> *HWA:*
> *But I think she's a bit, I think she's a bit gone for dementia though, because she said that she continues to drive although she now avoids long distance because she feels this is due to her own preference rather than a decline. Is she avoiding the thing that she's declined?* (Dementia unseen -)

Sally's decision to change her driving behaviour is positioned as a mechanism to hide her deterioration. By avoiding long distance driving she will not have to cope with an activity where she may struggle. Rather than position this action as a potential indicator of Sally's insight, it is used to illustrate that Sally is deteriorating but hiding from her decline. The power of the diagnosis as a positioning tool is illustrated by the statement, '*I think she's a bit gone for dementia',* suggesting that Sally's current presentation could be regarded as significantly worse than other people living with dementia.

Assumptions about the deterioration and stage of dementia are also applied to Sally's husband:

HWE:
Break there. But I think the husband is quite advanced. (Dementia unseen -)

The lack of information in the case study about Sally's husband leads to assumptions built on the knowledge about his diagnosis.

The assumed severity of his dementia results in the recommendation that he receives 24 hour care outside of his current home:

HWE:
Husband. He should be in a home. Because I think he ain't well. (Dementia unseen -)

The position aligns with the negative *Capable* sub-theme in *Able* but strongly indicates a negative *No dementia* position. The decision that Sally's husband requires 24 hour care is based on his diagnosis rather than any confirmatory evidence regarding his perceived lack of ability. The reaction to his diagnosis results in this incident of negative positioning within the *Dementia Unseen* theme.

The participants use empathy to position Sally and her husband when discussing attendance at a day centre:

HWC:
If that was me and my other half.. (Dementia unseen + 2nd)

HWB:
I'd wanna be with them too, yeah. (Dementia unseen + Confirm)

HWC:
Because your, that's what you've, you've like lived your life, you've lived your life with them so you'd wanna be like. You wouldn't wanna be separated would you? (Dementia unseen + Confirm)

The participants indicate that if they were attending a day centre, they would prefer to be with their partner rather than expected to attend separately. A positive *Doesn't matter* position is achieved as the couple's dementia is not considered to be a reason to justify their separation.

Lay people

A total of 38 positions were identified within the Dementia Unseen positioning theme. Positive positions accounted for 61% (38), neutral positions 5% (2) and negative positions 34% (13).

Dementia is presented as an indicator for positioning Sally against her husband:

LPB:
We don't know who's the worst. (Dementia unseen -)

The statement could imply the requirement to understand the stage of dementia for both members of the couple to assess their support needs, however, the question of '*who's the worst*' informs a negative *Doesn't matter* position. The ranking of the couple based on their individual dementia indicates that, to be positioned, their diagnosis undeniably matters.

Dementia is also used to make an assessment of their support needs:

LPF:
But they've both got, they've both got dementia. I think they would need, I think, some support should be there. (Dementia unseen – 2nd)

LPD:
I think they should have some, yeah. (Dementia unseen – Confirm)

Current abilities are not considered when assessing the need for external support as the presence of dementia automatically makes this a necessity.

The group consider their own driving behaviour when considering Sally's decision to stop driving longer distances:

LPA:
That's enough. When I, I that would be my preference you see. I wouldn't want to go that far. (Dementia unseen + 2nd)

LPB:
No, no. Well, I, I only drive as far as Colwyn Bay. (Dementia unseen + Confirm)

LPA:
Exactly. She's not. It's not because they can't drive. It's, it's just a preference.
(Dementia unseen + Confirm)

LPB:
No.

LPC:
Of course, it's a..
Yeah, it's a preference so, rather than a decline in her driving abilities.
(Dementia unseen + Confirm)

LPB:
I won't drive to Chester. (Dementia unseen + Confirm)

The participants empathise with Sally's decision by revealing their own self-imposed driving limitations. Sally's decision is not regarded as a consequence of her dementia or regarded as a decision only applicable to people living with dementia. By applying Sally's actions to their own, a positive *Dementia Unseen* position is achieved.

A gender stereotype is used to position Sally outside the context of her dementia:

> *LPB:*
> *And she's a woman. Women have to do everything.* (Dementia unseen + 2nd)

The proposal that Sally appears responsible for looking after herself and her husband is relocated, not as an indicator that his dementia is worse, but as confirmation of the participant's own bias. As the woman in the relationship, LPB suggests that it is only natural that she appears to be the more active member of the couple as these are the circumstances for women, without the presence of dementia.

The suggestion that Sally and her husband inform their church friends about their diagnosis leads to further positive positioning in the theme:

> *LPB:*
> *No, no, no, so they still treat them as normal.*
>
> *LPE:*
> *Well, but they are normal. That's just it. There's nothing wrong with these people.* (Dementia unseen +)

LPB's statement indicates the desirable position that Sally and her husband should be treated *'as normal'*. LPE demands a stronger perspective arguing that being treated as normal does not go far enough and that they must be accepted as *'normal'*. Although LPB's statement encourages positive positioning, it is LPE's language that actually achieves the positive position.

The discourse evolves into further considerations of being '*normal*':

> *LPE:*
> *You know, I just, I don't know, I'm probably on the wrong track but that's just my opinion going by what we've seen. They wouldn't want anybody there, interacting with their lives.* (Dementia unseen + Strengthen)
>
> *LPD:*
> *No. They don't want to be treated any different do they?* (Dementia unseen + Confirm)
>
> *LPE:*
> *They didn't want anybody.No, they didn't. They just wanted to be treated normal..*

LPE:

As they are normal, living with dementia. (Dementia unseen + Confirm)

LPA:

They are normal. (Dementia unseen + Confirm)

Although 'normal' may appear unremarkable as a position allocated to another person, it positively achieves the *No dementia* position in this context. The acceptance of the person living with dementia as '*normal'* is also indicated as a potential influence on other decisions (*They don't want to be treated any different do they?)* suggesting that the positive fulfilment of the *Dementia Unseen* theme may be efficacious for the positive achievement of other thematic areas.

Family members/carers

A total of 26 positions were identified within the Dementia Unseen positioning theme. Positive positions accounted for 4% (1), neutral positions 4% (1) and negative positions 92% (24).

Negative positions dominate the Dementia Unseen theme in the discourse of the group. One positive indicator of a participant looking to position people living with dementia beyond their diagnosis is observed:

FD:

Yes, yes. It doesn't suit everybody. It depends what type of person she is. If she's (Dementia unseen +) *pulled herself out of the bowls club thinking she can't be a treasurer, she's quite self sufficient.* (Able +)

FD indicates that it is important to consider the person beyond the dementia when decisions are being made, achieving a positive *Doesn't matter* position.

The people living with dementia from the AI outcome are positioned negatively within the *No dementia* sub-theme as the participants attempt to rank the people living with dementia based on the severity of the symptoms of dementia they observed during the film:

FD:

I think the man was best. Not the RAF, the other one. The one that worked in (site). (Dementia unseen – Confirm)

FC:

But he was repeating himself quite a bit, wasn't he? (Dementia unseen – Confirm)

FD:

Yeah. I saw him the best out of the four. (Dementia unseen – Confirm)

FB:

But he was younger wasn't he? About forty-six. He was very young then.

> *FC:*
> *Yes, yes. I had a bit of panics.*
>
> *FD:*
> *That's not long to go. He came out better than the others to me.* (Dementia unseen – Confirm)

The valuation of the person with the least observable symptoms as '*best*' positions the people living with dementia's personal attributes secondary to their dementia. The use of proposed symptoms ('*But he was repeating himself quite a bit')* to suggest that a person living with dementia is devalued compared to those without these symptoms opposes all positive indicators of the *Dementia Unseen* theme.

Symptoms that have been observed by the participants in their own relatives with dementia are used to describe all people living with dementia:

> *FB:*
> *Yes, my dad was the same. As if there's nothing behind them is there? It's as if, it's stuck. They look right through you and it's..* (Dementia unseen – Confirm)
>
> *FA:*
> *Yes, see right through and it's quite uncomfortable sometimes.* (Dementia unseen – Confirm)
>
> *FB:*
> *They're trying to works things out, they are? They are trying to work things out, aren't they? It's, it's, there's a look isn't there?* (Dementia unseen – Confirm)
>
> *FC:*
> *Well, I see them going absent as if they've not registered what you said. You're talking to them but..* (Dementia unseen – Confirm)
>
> *FD:*
> *Vague.* (Dementia unseen – Confirm)
>
> *FC:*
> *Yes, vague. We better do this, sorry.* (Dementia unseen – Confirm)

Although positions are initially allocated to the relatives discussed, this is expanded through the use of pronouns. Shared observations that '*they're trying to work things out*' and '*I see them going absent*' are used to describe all people living with dementia, based on possible real life experiences with individual people living with dementia. The allocation of these symptoms to describe all people living with dementia inform negative positions within the *No dementia* sub-theme.

Sally’s husband is regarded as having a potential negative impact on Sally:

> *FD:*
> *Maybe, Sally doesn’t like her husband in the end with the Alzheimer’s and she doesn’t want him there.* (Dementia unseen – Confirm)

Although Sally’s husband is positioned as a probable cause of harm, the position does not indicate a negative *No blame* position. As Sally’s husband now has dementia he is regarded as potentially unpleasant and therefore Sally may no longer want to be near him. This assumption is not supported by the information in the case study and therefore indicates a position based on the reported diagnosis, rather than any complimentary evidence.

Further negative symptomatic assumptions are shared and confirmed by the participants:

> *FA:*
> *Even though they both know each other and each other’s ways they could be at each other’s throats as well.* (Dementia unseen -)

> *FD:*
> *Fighting. Some can be violent, can’t they?* (Dementia unseen – Confirm)

The requirement to separate Sally and her husband is justified by the assumption that because they both have dementia, they are both likely to instigate violence upon each other. The positioning of Sally and her husband is extended by FD to include other people living with dementia outside of the case study. The assumption of violent tendencies achieves a negative *No dementia* position.

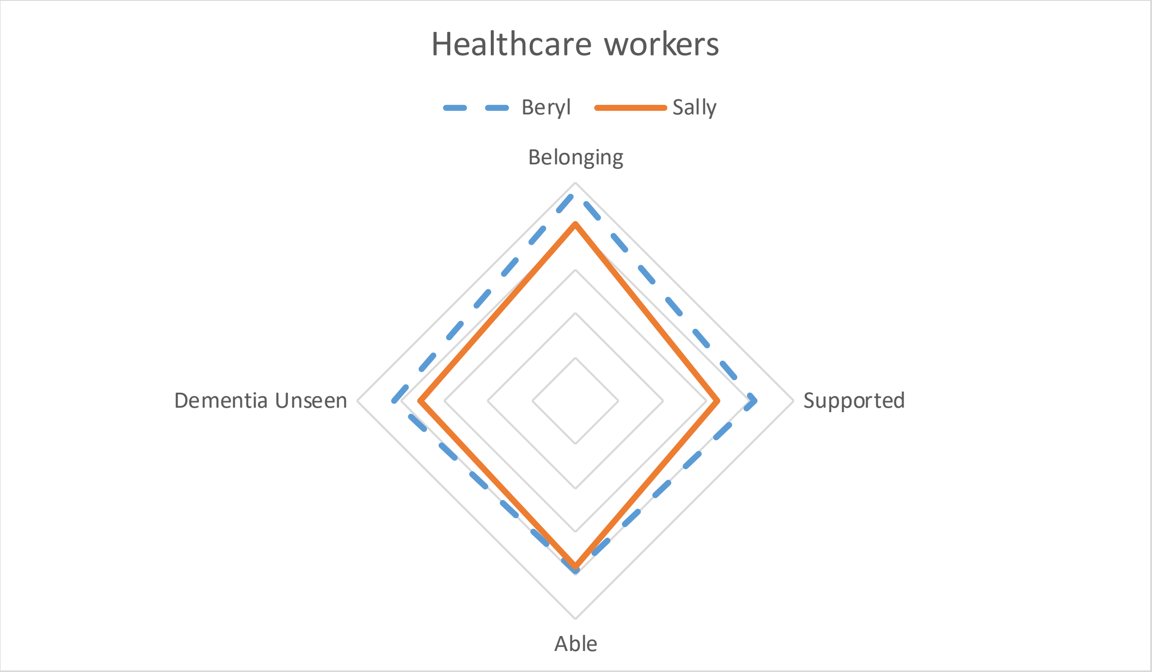
6.4 The impact of the AI outcome on the Balancing Framework

A comparative discussion is now presented regarding the positioning of Sally and Beryl. The discussion examines the pre and post AI outcome positions allocated during the group discourse. The positioning of each group is individually explored by thematic position with the Balancing Framework used as a visual indicator of positional changes between case studies.

6.4.1 Healthcare workers

The Balancing Framework indicates the differences in the groups thematic positioning of people living with dementia during both case study discussions. The Balancing Framework for the healthcare worker group is presented in Figure 32.

Figure 32: Balancing Framework results: Healthcare workers (02. 04. 2019)



The overall change in positioning values for this group from the Beryl to Sally case studies were:

- Incidents of positive positioning increased from 16% to 26% of all thematic positions.
- Incidents of neutral positioning increased from 54% to 35% of all thematic positions.
- Incidents of negative positioning decreased from 30% to 39% of all thematic positions.

The overall change reflects a positive change in the positioning of people living with dementia following the Delivery of the AI outcome. Increased negative positioning is also observed. How this applies to each thematic area for this group will now be explored.

Belonging

Positive positioning within this theme increased from 4% to 19% between the two case studies. The increase in positive positioning reflected a decrease in incidents of neutral positioning whilst the variation of negative positions lacked significance (54% to 56%).

Despite the increased number of positive positions, the healthcare worker group had the lowest increase of this value of all three groups between case studies. The growth of positive positions was established through the *Respect* sub-theme with participants directly referring to the AI outcome to suggest that Sally and the people living with dementia from the film should be respected.

Able

An overall increase in the occurrence of *Able* positions is observed between the two case studies, with 36 positions allocated during Beryl's case study and 54 positions in Sally's. Despite the increased amount of positions there is negligible change in any of the positional values for this theme. Although an increase in positive positioning is observed (22% to 24%), the result does not represent significant change. The result is similar to the other positional values, with negligible variation in neutral (44% to 46%) and negative (33% to 30%) positions.

Numerically, *Able* positioning by healthcare workers occurred more frequently than any other thematic positioning by the group. The 54 *Able* positions allocated in the second case study also represent the highest number of positions allocated to one theme by any of the three societal groups. The group's experience of ability in the care home is used to position both Beryl and Sally, often limiting the group's positive perspective of the abilities suggested in the original case study synopsis. Similar to the *No blame* sub-theme, during discourse when Sally is considered *Capable,* a negative *Capable* position is created for her husband.

Positive positioning tended to occur when Beryl and Sally's abilities were recognised, informing the *Capable* sub-theme. Positive *Superior* positioning remained absent in both case studies.

Supported

An overall decrease in positions within this theme was observed between the case studies (28 to 20 positions observed). A decreased occurrence of neutral positioning in Sally's case study (71% to 40%) related to increases in both positive (18% to 35%) and negative (11% to 25%) positions in this theme.

The healthcare worker group was the only societal group with an observable decrease in *Supported* positions during the second case study. This group were also the only societal group with an increased occurrence of negative positions within the theme.

Despite increased positive positioning, the discourse concerning *Purpose* tended to focus on lost activity and purpose rather than potential meaningful ambitions. The sub-theme *Encourage* was often addressed by suggestions of support that could be provided to both Beryl and Sally to involve them in activities. The positive elements of the sub-theme were neglected when not aligned with the requirement for meaningful purpose.

Dementia Unseen

There is a scarcity of Dementia Unseen positions allocated during Beryl's case study (6) with a significant increase for Sally's (28). The increase of positive positions in this theme (17%

to 28%) could be indicative of the greater numerical incidence of this theme's positions, as there is also an observable, and greater, increase in negative positioning (17% to 54%) within this theme. However, the context of positive positions does illustrate some discursive variations between the case studies, even if these are narrated inconsistently.

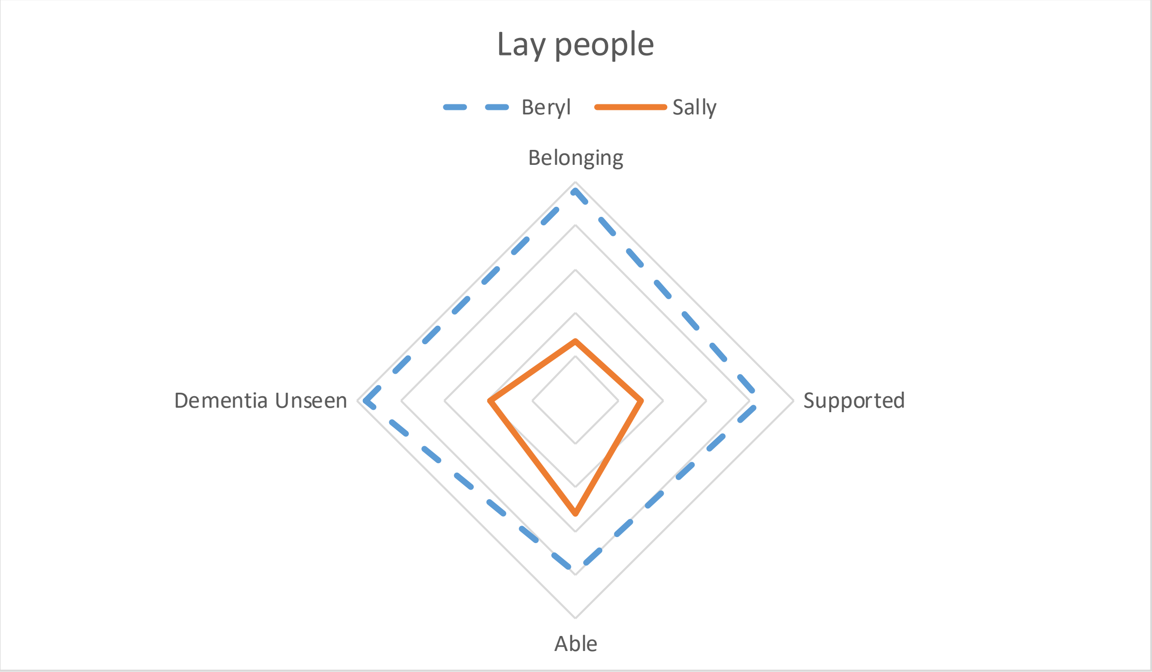
The increase in negative positioning represents the greatest percentile increase of this positioning value within the three groups. However, the overall occurrence of negative positioning was less than the occurrence in the family members/carers group (92%).

There is a paucity of Dementia Unseen positions provided by this group relating to the Beryl case study. Positive positions are allocated to Sally, generally through an acceptance of her individuality over her diagnosis. These positions reflect the affirmative requirements of *Doesn't matter* positioning. Positive *No dementia* positions are observed through the group's empathic reasoning, including a discussion when the group discuss their own potential objections about being separated from their partner. Positive positions within the latter sub-theme, however, are less evident in the general discourse.

6.4.2 Lay people

The Balancing Framework indicates the differences in the groups thematic positioning of people living with dementia during both case study discussions. The Balancing Framework for the lay people group is presented in Figure 33.

Figure 33: Balancing Framework results: Lay people (20.09.2019)



The overall change in positioning values for this group from the Beryl to Sally case studies were:

- Incidents of positive positioning increased from 12% to 63% of all thematic positions.
- Incidents of neutral positioning increased from 35% to 17% of all thematic positions.
- Incidents of negative positioning decreased from 53% to 20% of all thematic positions.

The overall change reflects a positive change in positioning of people living with dementia following the Delivery of the AI outcome. How this applies to each thematic area for this group will now be explored.

Belonging

Numerically, the number of positions dedicated to this theme in both case studies remains constant (33 to 35). The increase in positive positioning between the case studies is exceptional (3% to 73%) whilst negative positioning also significantly decreased (51% to 24%).

The lay people group has the highest percentile growth from negative to positive positions within this theme and also the highest overall occurrence of positive positions in the Sally case study for *Belonging*.

Positive *Respect* is achieved as the group appreciate Sally and her husband's continued involvement in their wider community and the value placed on their spousal relationship. The narratives from the AI outcome were used to link the relationship between Sally and her husband with Colin and his wife:

> *LPF:*
> *The, the second chappy, was it the second one? He said as long as I've got my wife in my peripheral vision.* (Belonging + Confirm)
>
> *LPD:*
> *That we like to see the bigger, that his wife was..in his peripheral vision. He was ha.., he was confident.* (Belonging + Confirm)

Able

There is a significant decrease in the number of positions related to this theme between the two case studies (53 to 31). An increase in positive positioning is significant (21% to 48%) although this movement is greater in the occurrence of negative positioning (79% to 23%). The movement between positional values also resulted in an increased occurrence of neutral positions (0% to 29%). This latter value is regarded equally to negative positions when entering data into the Balancing Framework, as neither represent the positive positioning described in the earlier AI phases. The movement from negative to neutral positioning, however, does illustrate a direction of discursive travel with greater alliance with the AI outcome's ideals than the group's previous positioning of people living with dementia.

The lay people group are the only societal group whose overall *Able* positioning decreased during the second case study. However, this group did have the highest percentage growth of positive positions within the theme. The AI outcome was used to justify the participant's positive positioning of Sally and her husband:

> *LPE:*
>
> *No, They'll be fine. At least, no, I still don't think they need it because (gestures towards TV) they could be young couple and the, there's, people we just looked at.* (Able + 2nd)

In considering the abilities of the people living with dementia within the AI outcome, members of the group embraced Sally's abilities as potential solutions to her current situation rather than as potential hazards, as they had previously suggested with Beryl.

Supported

The number of overall positions within this theme were constant (34 to 33). Positive positioning increased significantly (15% to 70%) whilst negative positions were erased from the discourse (29% to 0%).

The positional shift is clear as Sally's activities are positioned as having a meaningful purpose, whereas Beryl's had been regarded as unnecessary due to the perceived potential harm that could occur if they continued. Whilst it was suggested that Beryl should attend the day centre so that other people could be '*looking out for her*', proposals for Sally to attend were less protective with suggestions made that she should only attend if she wanted to or should not be asked to attend without her husband. Through the positioning of the people living with dementia in the AI outcome as having '*perfectly adequate lives'*, Sally's own perspective of her own and her husband's meaningful purpose is accepted.

Dementia Unseen

An overall increase in *Dementia Unseen* positions was observed between the two case studies (24 to 38). A significant increase in positive positioning (4% to 61%) subsequently affected neutral positions (46% to 5%) to a greater extent than negative positioning (50% to 34%).

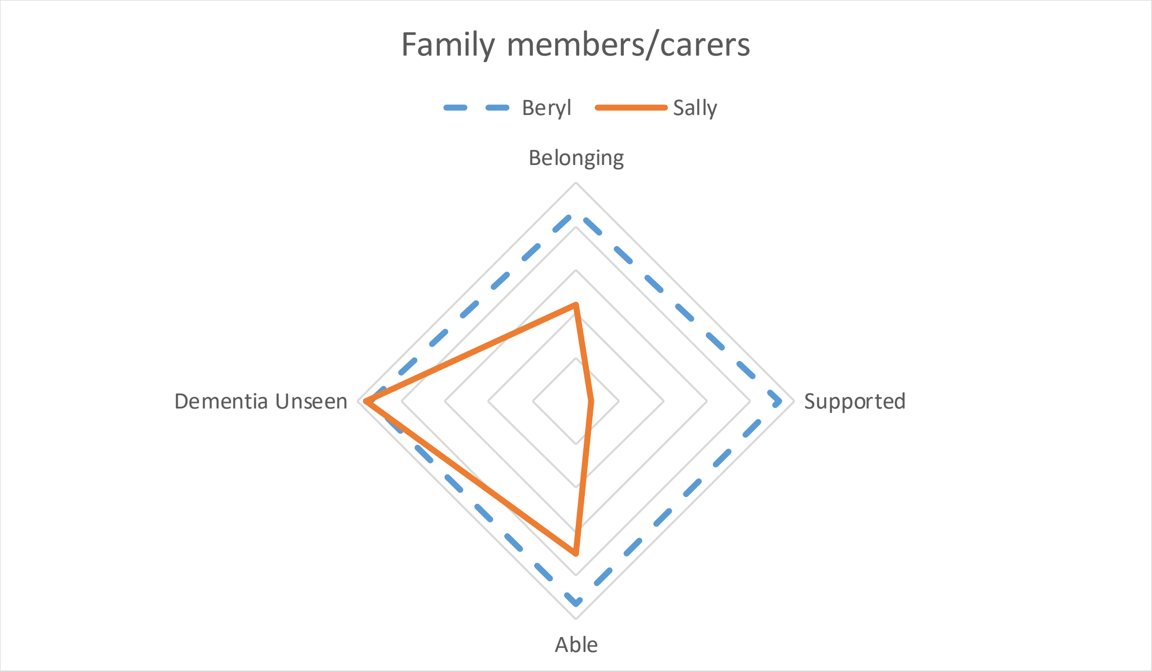
The lay people group had the greatest percentile increase of positive positions within this theme compared to the other societal groups. Critically, as the lack of experience of this group has been used to address a potential decline in interest for the *Able* theme, the same mechanism could also be applied to the positive positions within the sub-theme. For healthcare workers, a small increase was observed in positive Dementia Unseen positions (17% to 29%) whilst there was a slight decrease in the occurrence of positive positions in the family members/carers group (6% to 4%). The demand from the AI outcome to create positions were dementia *Doesn't matter* may be less challenging to a group of lay people, whose experience and knowledge of dementia may be limited.

Sally is positioned as being like the group themselves ('a woman'), unlike the positions previously allocated to Beryl (*'wandering'*, *'scared'*). The positions allocated in the Sally case study illustrate the group's perception of people living with dementia have changed, as the person is seen before the dementia. The '*normal* 'position is directly aligned to the positioning of the people living with dementia in the AI outcome.

6.4.3 Family members/carers

The Balancing Framework indicates the differences in the groups thematic positioning of people living with dementia during both case study discussions. The Balancing Framework for the family members/carers group is presented in Figure 34.

Figure 34: Balancing Framework results: Family members/carers (04. 12. 2019)



The overall change in positioning values for this group from the Beryl to Sally case studies were:

- Incidents of positive positioning increased from 8% to 39% of all thematic positions.
- Incidents of neutral positioning increased from 28% to 3% of all thematic positions.

- Incidents of negative positioning decreased from 64% to 58% of all thematic positions.

The overall change reflects a positive change in positioning of people living with dementia following the Delivery of the AI outcome. How this applies to each thematic area for this group will now be explored.

Belonging

The overall occurrence of *Belonging* positions doubled between the two case studies (8 to 16). An increase in positive positioning (12% to 56%) was achieved, primarily at the expense of neutral positions (38% to 0%) with a less significant decrease in negative positions (50% to 44%).

The family member/carers group was the only societal group to observe a significant increase in overall positioning within this theme.

Negative *No blame* positions were commonly achieved in the first case study with people living with dementia accused of hiding items in the home and making difficulties for their partners. Empathic attitudes were reserved for the carers in the situation, with participants able to draw upon their own experiences to illustrate their concerns and inform their positioning.

Although negative *No blame* positions were also evident in the positions allocated in Sally's case study, for example, Sally's decision to alter her driving behaviour would cause her to experience isolation, the increase in positive positioning was characterised by positions in the *Respect* sub-theme. The increased positive *Respect* was achieved through the group's regard for the spousal relationship and the belief that people living with dementia should be interacted with in a manner that they want, not how the person without dementia prefers.

Able

A small increase in overall positioning was observed in this theme (15 to 23). Although an increase in positive positioning was observed (7% to 30%), negative positions remained dominant (86% to 70%) in both case studies.

The high incidence of negative positions for both case studies occurs exclusively within this societal group. Healthcare worker's negative positioning remained consistent between the groups (33% to 32%) whilst a significant reduction was observed in the lay people group (79% to 23%). Similar to how the AI outcome provided minimal influence on the Able positioning of healthcare workers, it was unable to radically alter the negative positioning by this group. The lived experiences of this group, including the transition of their relatives from personal home to care home, are likely to have an ongoing influence on their positioning of people living with dementia even after the AI outcome has been viewed.

Supported

No significant change was observed in the number of overall positions within this theme (14 to 15). Positive positioning is radically increased (7% to 93%), with a reduction of negative positioning (29% to 7%) and the eradication of neutral positions (64% to 0%).

The incidence of positive positions is the highest percentile occurrence of a positive value in any theme within all three societal groups. The recognition that people living with dementia require meaningful activity and purpose informed many of the positive positions within the *Purpose* sub-theme. Positive positions were also evident in the *Encourage* sub-theme, although positively suggesting the requirement for purpose occurred more frequently than positions, which acknowledged the people living with dementia's current ability to fulfil this purpose.

The positions allocated to Sally and people living with dementia during the latter case study, illustrated a shift in the participant's consideration of this theme. Sally's activities were regarded as beneficial whilst they felt a day centre would be unsuitable for her purpose. The group agreed that Sally's positive *Purpose* should be decided by Sally, rather than external forces.

Dementia Unseen

A numerical increase of Dementia Unseen positions was observed between the case studies (16 to 26). Numerically, the occurrence of positive Dementia Unseen positions was unchanged between case studies (1) although the larger number of position generally represented a decrease in positive positioning (6% to 4%). Neutral positions declined significantly (31% to 4%) whilst a notable increase in negative positioning was observed.

The family members/carers group was the only societal group to observe no increase in positive positioning within this theme. Although the healthcare worker group observed a greater percentile increase of negative positioning (17% to 54%), the overall occurrence of negative Dementia Unseen positions was significantly greater in the positioning by family members/carers. The latter group was the only societal group with a percentile decrease in positive positions.

Sally was positioned similar to Beryl, with suggestions that dementia would mean that people without dementia would find her presence uncomfortable and that dementia was likely to create violent tendencies. Dementia was also regarded as the potential reason why Sally would no longer like her husband.

6.5 Summary

The AI outcome was shared with three societal groups to ascertain whether the people living with dementia's Design could influence the verbal positioning of other groups in society. The outcome of the positioning analysis illustrates clear differences in the positioning of people living with dementia in these groups, following the Design intervention. The AI outcome, created by people living with dementia, was observed to influence the positioning of people living with dementia by other groups although the effect on individual societal groups varied, depending on their previous experiences with people living with dementia.

The Delivery phase shared the outcome of the Discovery, Dream and Design phases of AI previously completed by a group of people living with dementia as a mechanism to positively influence the verbal positioning of people living with dementia. The Design was shared with three societal groups; healthcare workers, lay people and family members/carers. The three groups discussed an individual case study (Beryl) before viewing the AI outcome. Following the viewing, the groups discussed a further case study (Sally).

The discourse from the case study discussions was successfully analysed using the positioning analysis model, designed through the earlier stages of AI. The analysis successfully allocated positioning themes and values to the group's discourse, which informed the comparative analysis of verbal positions allocated to people living with dementia, between societal groups and individual case studies.

Analysis of Beryl's case study illustrated a comparative absence of the positive positioning of people living with dementia in all three societal groups. Neutral positioning dominated discourse related to the *Supported* and *Dementia Unseen* positioning themes. Negative verbal positions dominated the discourse related to the *Belonging* and *Able* themes.

Analysis of Sally's case study illustrated a positive change in the verbal positioning of people living with dementia in all three societal groups. The participants directly addressed the influence of the AI outcome on their positioning of people living with dementia during the discourse. Variation was observed regarding the effect of the AI outcome on compared societal groups and positioning themes.

Positive positions were articulated more frequently by healthcare workers, although the results in this group were minimal compared to other societal groups. The most frequently positioned theme in the healthcare worker group, *Able*, observed no significant change between case studies. The verbal positioning of lay people had the greatest observable change following the AI outcome with greater occurrences of positive positions occurring in all four positioning themes. Positive positioning was observed more frequently in the discourse of the family members/carers group although an increase in negative positioning occurred in the *Dementia Unseen* theme.

Chapter 7

Findings: Five thematic positioning identities as facilitators and barriers to positive verbal positioning as defined by Appreciative Inquiry

7.0 Introduction

This chapter continues to present the findings of how the outcome from an AI process with people living with dementia influenced the discourse of members of three social groups. The findings in this chapter focus on the aim of the thesis: What factors influence the verbal positioning of people living with dementia by members of society aware of the AI outcome?

The chapter will address the following finding:

4. Five thematic positioning identities as facilitators and barriers to positive verbal positioning as defined by AI.

Finding 4 introduces three themes, which conceptualise why individuals reacted differently to the AI film produced by people living with dementia and particularly, why some participant's discourse was closer to the vision of positive positioning shared by the people living with dementia compared to others . These conceptual themes are:

1. Practical experience
2. Emotional attachment
3. Positioning identity

The third conceptual theme explores the concept of evolving positioning identities, illustrating five identities that emerged from the case study discourse. The development of positional identities is synchronous with the generative influence of the AI outcome, influencing the acceptance and denial of positive positioning by individual participants. These outcomes are integral to the synthesis that follows in chapter 7.

The chapter will discuss the findings in relation to the themes of practical experience and emotional attachment. The five positioning identities will then be explored, with each participants allocation of positions illustrated in individual Balancing Frameworks with a discussion regarding their most prominent identity during discourse.

7.1 Findings

Three conceptual themes as direct influences on the positioning of people living with dementia emerged from the analysis of the positions allocated by the three societal groups. Two of these themes, identified through Bamberg's(1997) positioning levels and thematic analysis (Braun & Clarke, 2006) of statements, suggested a positional bias, concerned the participant's previous experience with people living with dementia. The two conceptual themes, which emerged are:

1. Practical experience
2. Emotional attachment

The third conceptual theme emerged from the thematic analysis of the positions. The third conceptual theme developed is:

3. Positioning identity

This third theme includes five conceptual identities, which establish the participant's susceptibility to altering their positioning of people living with dementia following the Delivery of the AI outcome and the discourse of other members in the group. The five conceptual identities are:

3.1 Stagnant positioner

3.2 Open positioner

3.3 Empowered positioner

3.4 Threatened positioner

3.5 Reluctant positioner

The three themes will now be presented with illustrations from each societal group, using the findings from the discussion groups regarding Beryl (pre-AI) and Sally (post-AI).

7.2 Practical experience

Participants entered the study with varying degrees of practical experience. This theme describes the 'hands-on' experience of providing practical care to people living with dementia. The healthcare worker group was identified as a societal group held together by their practical experience of working with people living with dementia. Family members/carers also have practical experience, although the scope of this experience may only include their relative with dementia. The lay people group was not presumed to have any practical experience with people living with dementia, although due to the growing numbers of people living with dementia in the Welsh population it was also presumed that some members of this group would have more practical experience than others. All groups provided verbal evidence of when their own practical experiences influenced their positioning of people living with dementia, which is observed in the reporting of the results. Although practical experience provides a factual account of an experience for the individual, it does not provide a scientific evidence base for how care should be universally delivered. Beattie *et al*, (2002) criticised the design of dementia services as often relying on the recommendations of people with practical experience rather than a stringently reviewed scientific evidence base. Similarly, the allocation of positions does not depend on an agreed evidence base but may be heavily influenced by the participant's previous practical experience of people living with dementia.

Healthcare workers

This group used the experience of working in the care home to consider their responses to the case study questions. Their role in the care home included the provision of significant assistance to people living with dementia to manage basic activities of daily living and this was alluded to when considering Beryl's needs. What the group considered to be practical difficulties in working with residents with dementia, was also considered as potential issues for Beryl's ability to continue living at home:

> *HWA (Healthcare Worker A):*
> *Or if she hasn't put it in her mouth. They hide them anywhere.* (Belonging – Confirm)

The suggestion that Beryl may hide her medication was based on HWA's insinuation that residents in the care home engaged in this behaviour and therefore, Beryl would repeat this behaviour as part of the collective 'they'. Similarly, Beryl was considered unlikely to accept assistance as residents in the care home did not always recognise the need for assistance:

> *HWC (Healthcare Worker C):*
> *So what if she doesn't want, like, we've got the likes of some of them here that won't actually. They won't ask for help. The likes of like 'I don't need it'.* (Able=)
>
> *HWD (Healthcare Worker D):*
> *(inaudible) of dementias has gone as well sort of thing.*
> *Yeah, cause they think they've…we don't need you.* (Able= Confirm)

Participants believed that people living with dementia were unable to recognise their need for assistance, as evidenced for this group through their care home experience, was drawn upon following the Delivery of the AI outcome to position Sally and her husband:

> *HWB (Healthcare Worker B):*
> *But some of them like, think they can care for each other.* (Able – 2nd)

HWB suggested that as residents are unable to care for each other independently, in the care home that the healthcare workers are employed, Sally and her husband, as two other people living with dementia, are also incapable of doing this. The bias of this positioning was identified by HWE:

> *HWE (Healthcare Worker E):*
> *We're looking at it as we're carers.*

The participant's recognition of a potential bias in their positioning due to their practical experience encourages the group to view the case study beyond the confines of their own contact with people living with dementia. The Delivery of the AI outcome constitutes a further practical experience for the group, albeit the viewing of people living with dementia's personal perspectives of their practical experience rather than the physical practicality of the group's employment. The AI outcome is directly referenced by HWE when Sally's position is influenced by this latter practical experience rather than the context of the care home:

> *HWE:*
> *I think if she thinks she can't be a treasurer she can't do it, she can't just play anymore. (Able -) Perhaps maybe being a treasurer gave her a sense of worth like that woman was talking about on the video. (Supported = 2nd)*

Discourse related to their practical experience in the care home, rather than Sally's case study, illustrates the power of this experience and its influence on the participants when considering what would happen if their residents did not receive their support:

> *HWC:*
> *Well, they wouldn't be fee..They wouldn't be like eating, drinking, having a wash.*
>
> *HWA:*
> *Taking themselves to the toilet..awful and like the socialising.*
>
> *HWD:*
> *Aggressiveness..we've a couple of residents..think?*
>
> *HWA:*
> *Or if they had a fall or anything.*
>
> *HWC:*
> *They'd hurt themselves.*

Fatalistic predictions describing '*carnage*', '*aggressiveness*' and lives independently devoid of activities of daily living, safety and socialisation are borne from the practical experiences of this group and are key informants of their subsequent positioning of people living with dementia. The influence of this theme on the positioning of people living with dementia was observed during the discourse of both case studies in the healthcare worker group.

Lay people

Reference to practical experience does not occur in the discourse of all members of the lay people group during Beryl's case study. Only two members of the group are recognised as having relatable practical experience. LPA's experience stems from her previous employment as a home carer when some of the people she visited were people living with dementia. This experience is used to position Beryl regarding her potential behaviour, if allowed to continue living at home:

> *LPA (Lay Person A):*
> *Well, I think she'll deteriorate and go worse and worse…put her knickers in the microwave like this lady used to…that I used to…* (Supported –)

LPA's practical experience illustrates potential safety concerns that she had during her employment, which are now used as reasons to limit Beryl's activities:

> *LPA:*
> *Another lady I knew, she stuck an electric kettle on the gas.* (Dementia unseen –)

The singular experiences of people living with dementia met during this practical experience are also expressed more directly as symptomatic of all people living with dementia:

> *LPA:*
> *Don't know day or night you see. That was what was happening to this lady and then the other was setting things on fire (inaudible).* (Dementia unseen –)

LPA's implication that all people living with dementia are disorientated to time is linked to further safety concerns. Her practical experience provides what appears to be an authoritative position within the group resulting in her allocated positions receiving the joint highest number of confirmed positions (7) during the Beryl case study discourse.

The practical experience of LPD does not include a person living with dementia. This experience is related to her father previously residing in a warden-controlled bungalow. Due to the familial connection, her experience aligns more directly with the conceptual theme of emotional attachment, although references to practical experiences are also implied:

> *LPD (Lay Person D): :*
> *And I have, I have concerns about the warden control because it seems to have disappeared. They don't have a daily call now. When they call for help it goes to some centre.*

LPD references possible practical difficulties her father experienced in warden-controlled accommodation to inform her decision making regarding Beryl's situation. LPD does not reference her practical experience as regularly as LPA but is allocated more confirm positions by other group members when this experience is shared.

The analysis and subsequent allocation of discourse relating to emotional attachment or practical experience was a complex process, which was predominantly informed by level 3 of Bamberg's positioning analysis (described in 2.4.3). This example of LPD's discourse illustrates the complexity of the analysis as her observations were grounded in her experiences with her father. On a surface level, this discourse is emotionally driven and during the earlier levels of analysis, I discussed with the supervisory team that there was a tangible difference in how LPD positioned herself and her allocation of positions compared to other lay people due to this emotional attachment. The level 3 analysis was completed by breaking the transcript into connected storylines, supporting the analysis of smaller sections of discourse. During the previous analysis, LPD's discourse in this example had been coded as indicative of her emotional experience with her father. However, when taken within its storyline, despite the emotional connection of 'concerns', the discourse is more aligned to the practical experience of warden controlled environments. This level of analysis complicated the clarity of the analysis as individual participants could not be aligned solely to certain experiences (and later, positioning identities), which was crucial to understanding why their allocation of positions was unstable.

The Delivery of the AI outcome provides an observable practical experience for all members of the group, which results in a radical shift in positioning, with this practical experience directly referenced as an influence:

> *LPE (Lay Person E):*
>
> *Those, those people. Thinking of them. Young and able and they were, they were just like..* (Supported +)
>
> *LPD:*
>
> *Put their point over well, didn't they?* Supported + (Confirm)
>
> *LPE:*
>
> *And they all still worked with jobs. They were still doing a job.* Supported + (Confirm)

The experience of Delivery prompts the group to consider the practical experience of people living with dementia beyond the confines of LPA and LPD's experiences. Watching the AI film empowers the group to view the people living with dementia beyond their diagnosis, but as people. The group are further empowered to share their practical experiences as people, rather than only considering experiences of dementia or disability, to influence their positioning of people living with dementia:

> *LPE:*
> *So, keep them independent, no bother. Sally can still drive, I don't think, she's fine.* (Supported +) *Now avoids long distances. I assume we all do that. She feels this is due to her own* (Dementia unseen +) *preference rather than. I think her driving's fine, I think, personally, I don't, I think, she's, they must be on..*
>
> LPF *(Lay Person F):*
> *Well, there are a lot of people as they get older..* (Dementia unseen +)

LPF recognises that it is the practical experience of many older people to limit their driving as they become older. This is applied to Sally as an indicator of good insight. The position is informed by the practical experience of older drivers rather than a practical experience of drivers with dementia.

The validity of assessing Sally's situation through the information provided in the case study is also scrutinised:

> *LPF:*
> *Really, it doesn't give you a, a great background really. It doesn't, does it?*
>
> *LPE:*
> *We don't need it though, after watching that film.*

HWF's questioning of the case study indicates her belief that knowing Sally has dementia is not sufficient to consider her needs. This belief was not voiced during Beryl's case study and only considered following the practical experience of Delivery. HWE illustrates her high regard for the AI outcome, suggesting the practical experience has empowered their insight into the experience of dementia.

Family members/carers

Practical experience is readily aligned to the emotional attachment theme within the family members/carers group as the majority of the former experience's concern the participant's relative with dementia. Recommendations during Beryl's case study discussion are informed by positive practical experiences with these relatives:

> *FC (Family member/carer C):*
> *A day centre is a good idea. You come home to something that you recognise.* (Supported =)

Through the practical experience of having a relative with dementia, members of the group had also built relationships with other carers in similar situations. The narratives of these practical experiences were also included in the discourse when considering potential barriers to achieving well-being for people living with dementia:

> *FC:*
> *(points to A) You were saying that, erm, there was somebody that went into a home and they just went into themselves because they weren't having any. He wasn't having any stimulation there, as such, so it is difficult but I still think if they can, it's important that they can be in their Cynefin.* (Supported =)

The Delivery of the AI outcome presents an insight into the practical experience of dementia from the perspective of four people living with dementia. The observation of the AI outcome provides further practical experience to the group, which is referenced whilst discussing Sally's case study:

> *FC:*
> *Yes, but again, as she says (points to video) if we say, if we say 'no', we say 'no'. And that's quite difficult because they've made a decision so you can't control them and she doesn't want, she says don't control us if we say 'no', we mean no.* (Supported + Confirm)

FC alludes to potential conflict between the AI outcome and her own practical experience. She recognises the people living with dementia's desire to make their own decisions but also acknowledges that relinquishing control to people living with dementia would be '*quite difficult*'. Her previous practical experience did not present her with the opportunity to consider the people living with dementia's desire to have this control, whilst her new practical experience, through AI, has provided her with a new perspective, resulting in positive positioning.

Following Delivery, FB also referred to other practical experiences, not directly related to people living with dementia, to influence the allocation of positions:

> *FB (Family member/carer B):*
> *And my mum's like that now but she hasn't got dementia.*
>
> *FC:*
> *Exactly and that could be more to do with her age.* (Able + Confirm)

FC confirms a previously allocated positive position in the discourse, whilst accepting the validity of FB's practical experience with her mother as relevant to the case study. Although the AI outcome had a negligible effect on the *Dementia Unseen* theme in this group, the application of this practical experience to inform the positioning of people living with dementia only occurs in the Sally case study. This underlines the potential influence of practical experience but also illustrates a contextual expansion of what is considered practical experience following the AI outcome.

7.3 Emotional attachment

Participants entered the study with varying degrees of emotional attachment. This theme describes experiences relating to people living with dementia that have had an emotional effect on the participant. The healthcare worker group was expected to have practical experience but no presumptions were made regarding their emotional attachment to this experience or experiences with people living with dementia outside of paid employment. Family members/carers were presumed to have emotional attachment as they were all related to people living with dementia. The lay people group was not presumed to have any emotional attachment with people living with dementia, although due to the growing numbers of people living with dementia in the Welsh population it was also presumed that some members of this group would have more emotional attachment than others. All groups provided verbal evidence of when their own emotional attachments influenced their positioning of people living with dementia, although this was less evident in the healthcare worker group. Similar to practical experience, emotional attachment provides a factual account of an experience for the individual, it does not provide scientific evidence. The emotional impact of a person's experience was observed to directly influence their positioning of other people living with dementia.

Healthcare workers

Whilst practical experience was clearly referenced during both case studies within this group, the influence of emotional attachment was generally lacking. There were no examples in the discourse relating to the practical experience of caring for people within the care home that suggested an emotional impact on the group members. However, the introduction of family members into the discourse did illustrate a minor influence of emotional attachment on participants:

> *HWE:*
> *But then..a centre. If she was at centre, she'd have too much time for her there and her independence gets taken away.* (Supported -)
>
> *HWF:*
> *Depends what centre is though. Because my Nana goes to (name), a lunch thing and that's a centre, isn't it?*

HWF introduces her Nana to counter the suggestion that all day centres result in reduced independence for the attendee. HWF's reference to Nana indicates her objection to her family member being positioned within this negative frame. By doing so, this emotional attachment, provides a potential pathway for people living with dementia, in similar situations, to avoid similar negative positions.

The relative absence of emotional attachments relating to people living with dementia impacting on the positioning of people living with dementia in the healthcare worker participants does not indicate an absence of emotional capacity within his group. The group was identified through their practical experience of healthcare work, and their relationships with each other exist through this mechanism. The group exists to practically support people in a care home and the influence of their roles in this context is evident during the case study discourses. Healthcare workers occasionally spoke about their own family members in the discourse, illustrating a more emotional attachment, but this was rare, reflecting the groups relationship as practical co-workers rather than an emotional absence in individual group members.

Lay people

The emotional attachment is observed in the narrative of LPD who refers to her father, who lived in a warden-controlled bungalow, to inform her positioning during the Beryl case study. The emotional security she experienced due to her father receiving daily carer calls, as well as the social appreciation regarding this support for her father, is used as evidence to support the position that Beryl requires more carer input:

> *LPD:*
> *I think so. I just, I just thinking about my father and how he would have appreciated, perhaps it was only half an hour in the morning and half an hour, teatime…and how much at ease we felt as a family*

There are no attempts to reject any 2nd order positions allocated by LPD during the Beryl case study. Although the practical experience of LPA resulted in more confirmed positions, the other group members were less likely to counter an emotional attachment suggesting that each experience is perceived differently but equally respected.

Other members of the group use LPD's emotional attachment to inform their own positioning of Beryl, whilst incorporating an emotional context:

> *LPE:*
> *(Name – pointing to D) she's got it from her dad. Dad. But he didn't have dementia but even so he still had the care didn't he? Better care than this poor lady's having, so again, it's the care, that, she's getting.* (Belonging -)

The presentation of Beryl as a '*poor lady*', emotionally charges her situation, elevating her needs beyond the practical. This emotionally based discourse results in a negative position as Beryl is regarded as isolated and powerless. The position is then confirmed by LPD, who originally influenced the position through her emotional attachment, which other members of the group are reluctant to challenge due to the positions emotional meaning to LPD.

Following the AI outcome, as the context of practical experience expanded, a similar outcome was observed to a lesser degree, relating to emotional attachment:

> *LPB (Lay Person B)::*
> *And she's a woman. Women have to do everything.* (Dementia unseen + 2nd)

LPB's suggestion that women are more active than their male spouses is based on her perspective of practical experience It represents a belief, which is the outcome of emotional attachment, which can be applied to any woman irrespective of dementia.

Family members/carers

The emotional attachment is clearly referenced within the discourse of this group with suggestions that the case study's questions about Beryl, are asked from the wrong perspective:

> *FB:*
> *It's very difficult for the partner, isn't it? It's worse. (Belonging -)*
> *It's hard work, physically and mentally.*

The group's shared background, independent of their employment, is their experience of having a relative with dementia. Each member has observed their relative cognitively deteriorate into the later stages of the disease. The emotional impact drives much of their discourse and although the latter example suggests the placement of the carer's emotional needs over the person living with dementia's, the group also consider how their own actions may have negatively impacted on the emotional state of their relative:

> *FC:*
> *There was an area in the home where she would have had her hair done but she thought she had gone out of the home and instead of just saying 'oh, yes', I would go 'no, you've just been to there'.But I'm so angry with myself now, that I did that, you know? I'm trying to get information, how to..*

FC recognises her actions as potentially damaging for her mother. The emotional impact of this behaviour on herself is considered with a caveat that she does require more information.

FC implies an emotional learning through these devastating experiences but acknowledges a need for further education.

7.4 Positioning identities

Participant's movements between positioning values before and following the AI outcome is indicative of a positional identity. Similar to positions, these identities are ephemeral, with individual's moving between identities during discourse. Throughout the discourse, individuals are illustrated to possess dominant identities, which influence their susceptibility to the influence of the AI outcome on their positioning of people living with dementia.

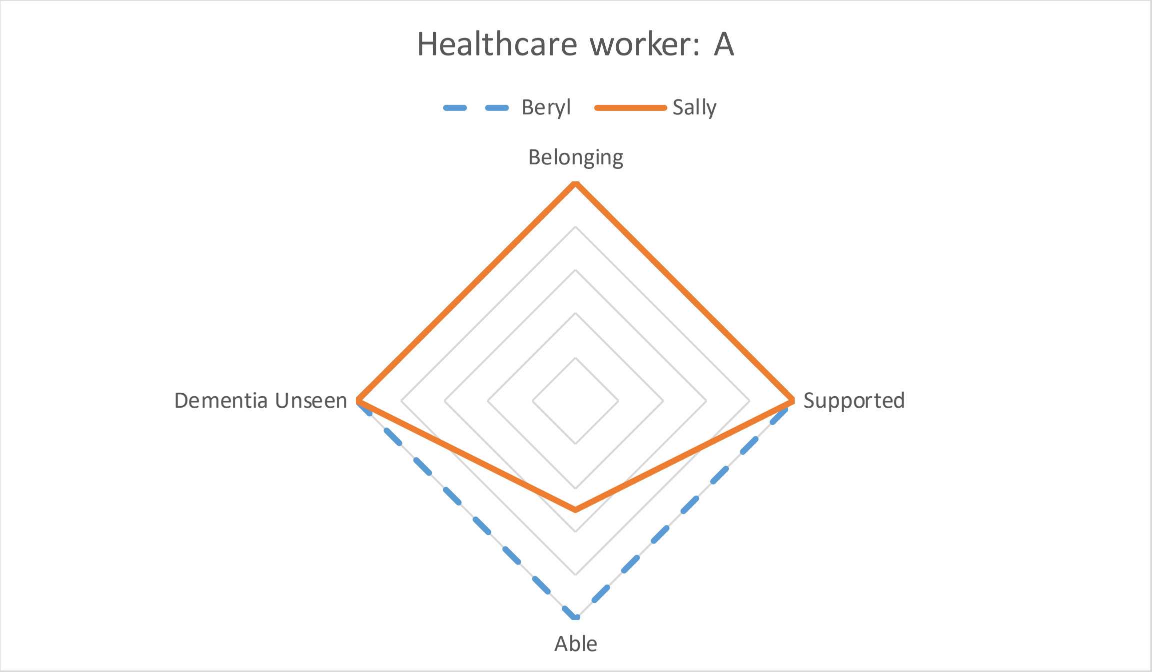
The five positioning identities will now be explored. The five identities are:

- Stagnant positioner
- Open positioner
- Empowered positioner
- Threatened positioner
- Reluctant positioner

Each participant is presented under their dominant positioning identity, incorporating discursive examples from the case study discussions and the individual results of their Balancing Framework.

The Balancing Framework for each participant displays the results for the positions during both the Beryl (pre-AI) and Sally (post-AI) discourse. This provides a visual indication of whether the participant's positioning of people living with dementia has altered following the presentation of the AI outcome. A blue dashed line on the Balancing Framework represents the positions allocated during the Beryl case study. An orange line represents the positions allocated during the Sally case study. The Balancing Framework in Figure 35 presents the positions allocated by HWA. The dashed blue lines in this framework for the themes of Belonging, Supported and Dementia Unseen cannot be observed as the orange lines are in the same position on the framework. This indicates that the positions offered in the Sally case study for these themes are unchanged from those allocated in the Beryl case study. For the theme of Able, the orange line is closer to the centre of the Balancing Framework than the dashed blue line, indicating that the positions allocated during the Sally case study for this theme are closer to the positioning advocated by people living with dementia during AI, than those allocated by HWA in the Beryl case study.

Figure 35: Balancing Framework: HWA



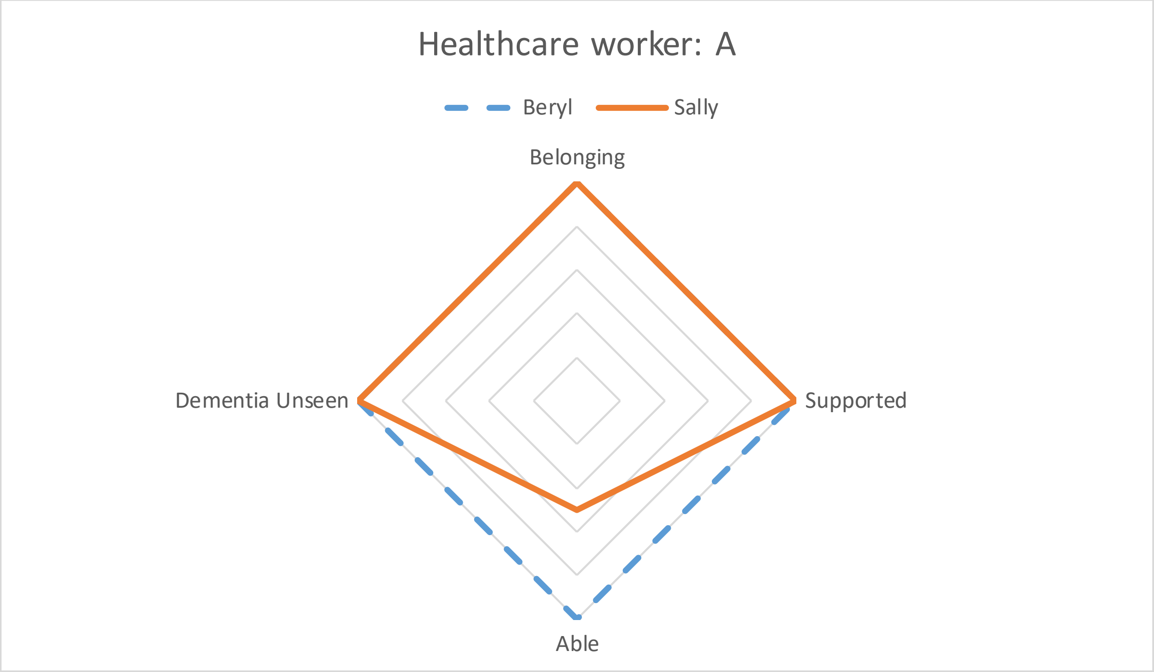
7.4.1 Stagnant positioner

This identity indicates participants who are resistant to influence. The resistance to influence applies to the AI outcome and the positioning by other following the Delivery of the AI outcome. A stagnant identity suggests the participant will be less likely to adopt new perspectives regarding the positioning of people living with dementia. Stagnant positioners have minimal influence on the positioning of other group members.

Healthcare workers

Increased positive positioning within the Able theme following the AI outcome is indicated in the Balancing Framework (see Figure 35) for HWA but otherwise, the positioning values are stagnant between case studies:

Figure 35: Balancing Framework: HWA



The number of allocated positions is relatively unchanged between case studies (19 to 20) although an increase in positive positions (0% to 21%), predominantly in the *Able* theme, is negated by an increase in negative positioning overall (40% to 53%). HWA is allocated less confirm positions between case studies (8 to 5), indicating that whilst other members of the group are altering their narrative, HWA is being left behind. HWB confirms 5 of HWA's positions in the Beryl case study but does not confirm any for Sally. Whilst HWA's positioning is unchanged, HWB has a dominant open identity, whose new perspective opposes HWA's stagnancy. HWA attempts six 2nd order positions to decrease the positioning value of the discourse during the Sally case study. Five of these 2nd order positions are rejected by other group members as they embrace positive positions.

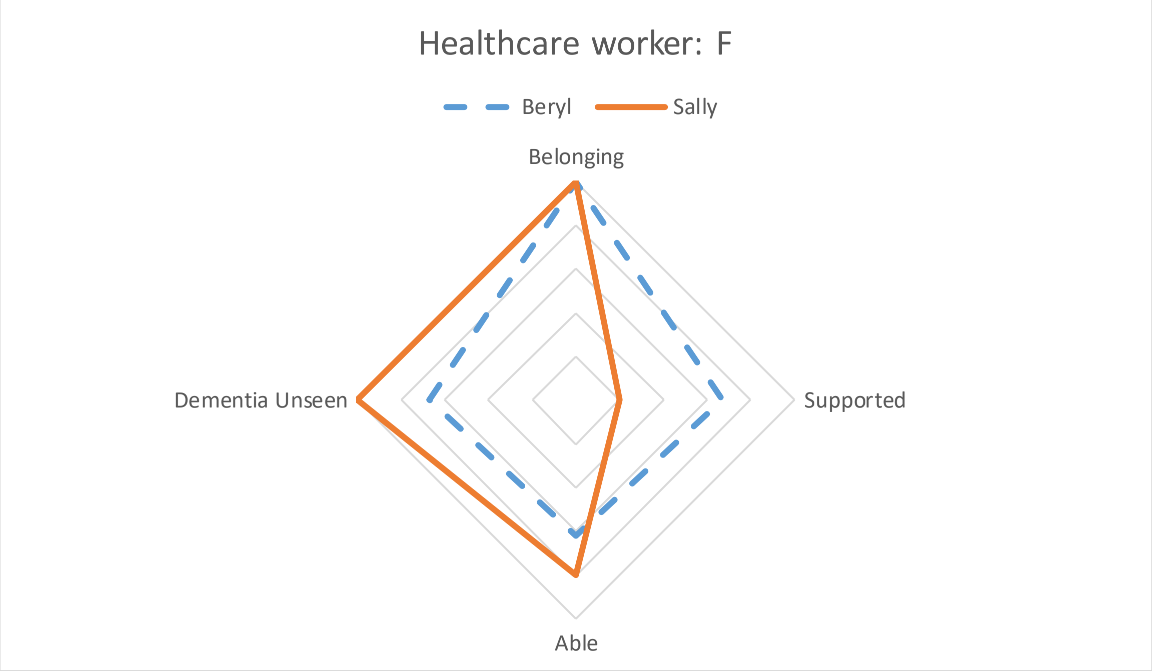
Despite this dominant stagnant identity, HWA is the first member of the group to offer a 2nd order position to indicate a positive change following the AI outcome:

> *HWC:*
>
> *Yeah, they've been in. They've asked for help. And if they're asking for help, they obviously need it.* (Able = Confirm)
>
> *HWA:*
>
> *How do you know?* (Able + 2nd)

HWA's challenge illustrates an awareness of a changing narrative following the AI outcome but the initial desire to enact the new narrative is not repeated during the subsequent discourse.

HWF illustrates greater movement between themes following the AI outcome, although there is less positive positioning within the *Dementia Unseen* and *Able* themes (see Figure 36). The positioning values between themes suggest a stagnant identity in the overall positional effect of HWF's discourse.

Figure 36: Balancing Framework: HWF



There is minimal change in the number of overall positions allocated between the two case studies (17 to 18). The occurrence of positioning values within these overall positions illustrates the lack of development between the two case studies with positive (5 to 6), neutral (7 to 6) and negative (5 to 6) values unaffected by the Delivery of the AI outcome. This consistency is also observed in the positioning values confirmed by HWF with each values receiving a confirm position on one occasion in each case study discourse. Both case studies result in four attempted 2nd order positions with the only observable change being one (of the four 2nd orders) attempted 2nd order to increase positive positioning for Sally, compared to four attempts to decrease positive positioning for Beryl.

<u>Lay people</u>

There were no participants in the lay people group with a dominant stagnant identity. However, although the identity was not dominant, as discourse developed, individual participants transferred between identities and stagnant positioning was observed. LPA's has a dominant open identity but when influenced by LPD's dominant threatened identity, there is an observed repetition of thematic positioning between case studies:

> *LPD:*
>
> *No, I thought they need some, perhaps have some time apart.* (Dementia unseen – 2nd). *I thought they needed some time away from each other.* (Dementia unseen – Strengthen)
>
> *LPA:*
>
> *That, that's what we said. If they went to the be, to the centre, on, on different days.* (Dementia unseen – Confirm)
>
> *LPD:*
>
> *You know she needs, we don't know how bad each of them is, do we? And one could be a lot worse than the other and I think that the worry of the, the worry of the other, they, they, they'd benefit from some time away to just think for themselves.(Dementia unseen – Confirm)*

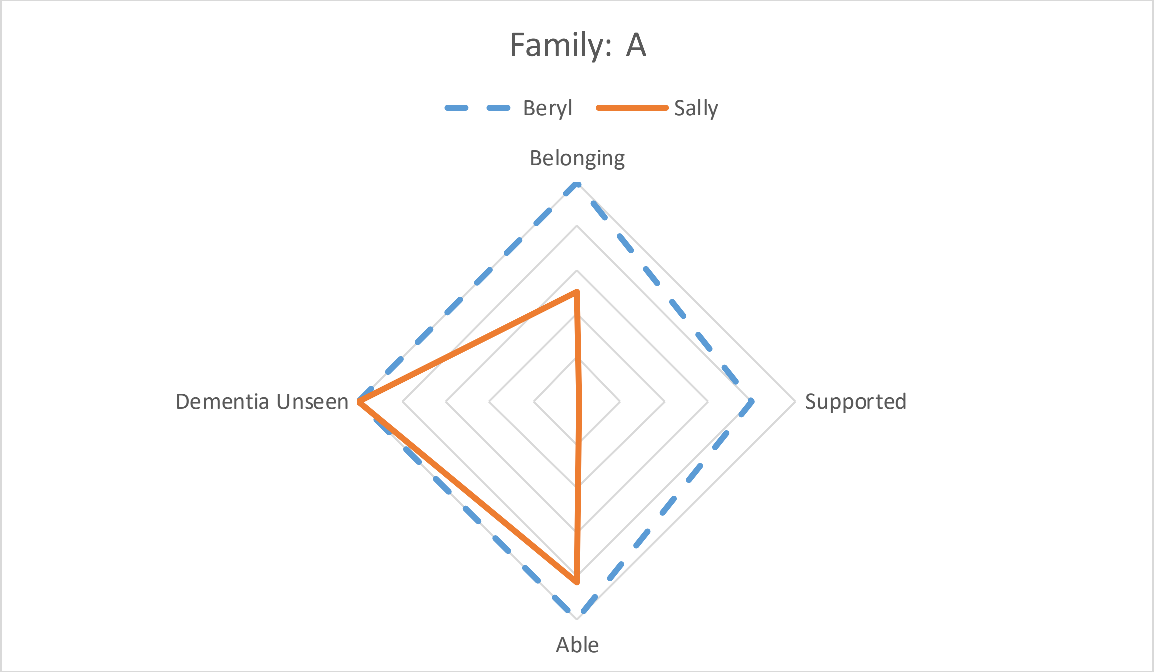
LPD attempts to create an alliance with LPA based on their shared practical experience. Whilst LPD's negative positioning aligns with her threatened identity, LPA's confirmatory position is not activated due to threat but represents her return to pre-AI outcome positioning, providing a stagnant identity during this period of discourse.

Family members/carers

All family members/carers experienced changes in their positioning, particularly relating to the *Supported* theme. The dominance of *Dementia Unseen* and *Able* positioning in Sally's discourse provided clarity regarding the dominant identities of the group.

FA's Balancing Framework (see Figure 37) indicates a positive movement within all the thematic areas with the exception of *Dementia Unseen*.

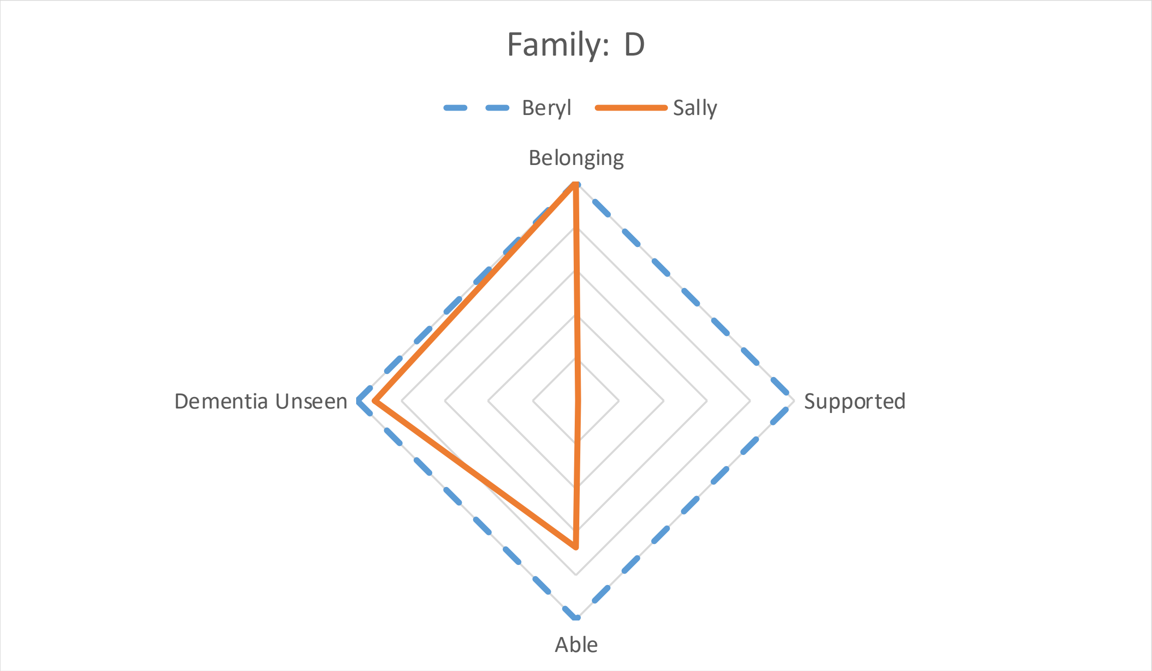
Figure 37: Balancing Framework: FA



A small increase is observed in the overall allocated positions in Sally's case study (12 to 16). An increase in positive positioning is also observed (8% to 25%) but the stagnant identity is informed by the continued dominance of negative positions (83% to 75%). FA continues to confirm negative positions with a similar regularity in both case studies (5 to 6). Whilst only one attempted 2nd order is observed for Beryl, which represents an attempt to decrease the positioning value, movement is observed. For Sally, six 2nd orders are attempted which are evenly allocated to increase and decrease the positioning value (3/3). FA's attempts to allocate 2nd order positions are rejected on 4 (from 6) occasions illustrating a new narrative for other participants whilst FA remains stagnant within the positioning values.

FD's Balancing Framework (see Figure 38) is observably similar to FA's, albeit with a minor positive change to *Dementia Unseen* and no change observed in *Belonging*.

Figure 38: Balancing Framework: FD



An increase is observed in overall allocated positions (13 to 17). Negative positioning remains dominant between case studies (77% to 76%) and although there is an increase in positive positioning (0% to 18%), the baseline of 0% may only improve or remain stagnant. No changes are observed in attempted 2nd order positions with both case studies including one attempt to increase positive positioning and three attempts to decrease the value. In both case studies, FD rejects 2nd orders allocated by FA and FD attempting to increase positive positioning.

The stagnant negative positioning, which dominates the identities of FA and FD is illustrated in the discourse of both case studies. For Beryl, the participants confirm negative *Able* positions to suggest she requires 24 hour care:

> FA:
>
> *It would be difficult to see her staying on her own in the bungalow.* (Able – Confirm)
>
> FC:
>
> *For long.* (Able – Confirm)
>
> FA:
>
> *Yes, without her going into a home or that she had family living with her. Being on her own she only has ten minutes everyday so I can't see it carrying on that she would be on her own in the bungalow for longer.* (Able – Confirm)

In Sally's case study, the AI outcome is overlooked as practical and emotional experience is used as a confirmatory device to establish behavioural traits for people living with dementia including Sally and her husband who '*could be at each other's throats as well':*

> FA:
>
> *Even though they both know each other and each other's ways they could be at each other's throats as well.* (Dementia unseen -)
>
> FD:
>
> *Fighting. Some can be violent, can't they?* (Dementia unseen – Confirm)
>
> FA:
>
> *Violent. I remember mum, many times that my dad went on, was going on her nerves and that, not that she would even do anything. She would do it for fun but he would (tightens his fists).* (Dementia unseen – Confirm)

Although the AI outcome is not ignored, it is not directly used as a mechanism to consider the positions of Sally and her husband. Without this influence, positioning occurs similar to Beryl's case study due to the stagnant identity.

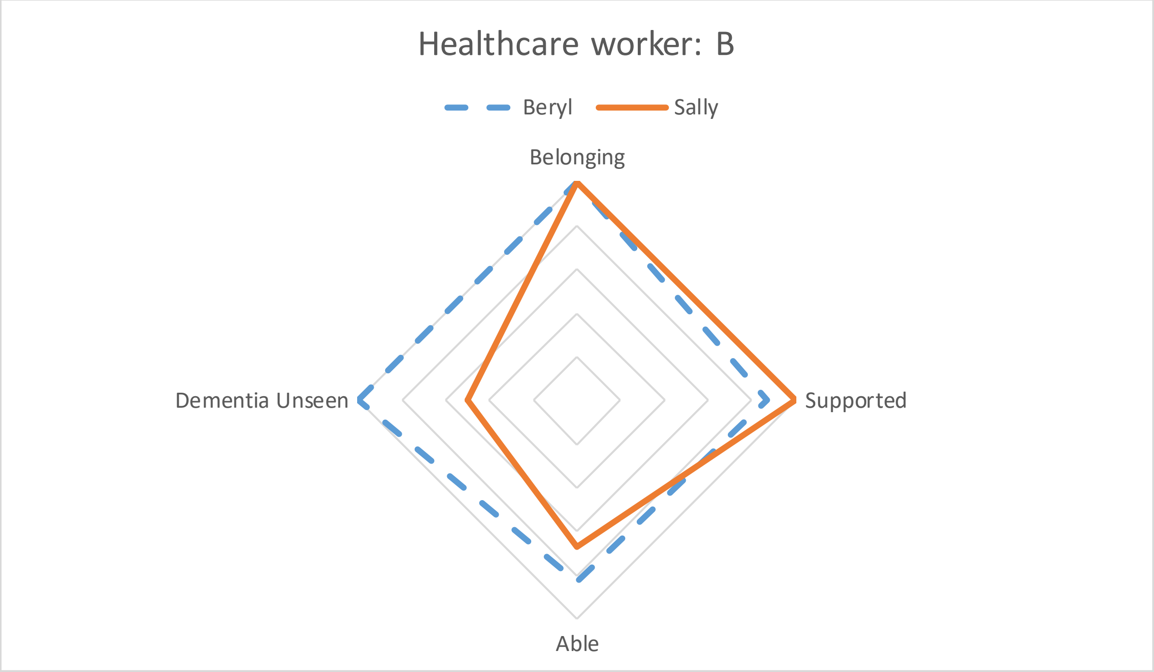
7.4.2 Open positioner

This identity suggests a positioner who is not burdened by their previous beliefs and is therefore willing to offer new positions. An open positioner may not radically move in their positioning values for all themes between case studies but their discourse, and response to the discourse of others, indicates they are willing to access new perspectives. They are influenced by the positions of others due to their openness but do not tend to influence the positions of other group members, unless they are also open positioners.

Healthcare workers

No changes were observed in HWB's positioning within the *Belonging* theme following the AI outcome whilst there was a marginal decline in positive values for *Supported* related positions. Her dominant open position was observed in the increased positivity in the remaining themes, illustrated in Figure 39.

Figure 39: Balancing Framework: HWB



HWB allocates fewer overall positions in Sally's case study (19 to 12). The numerical growth of positive positions between case studies (2 to 4) is more clearly demonstrated when expressed as a percentage within overall positions (11% to 33%). HWB confirms an increased number of positive positions in Sally's case study (1 to 3). In both case studies, HWB confirms the positioning values of four other groups members, illustrating an openness to listen and accept the positions allocated by others. During Beryl's case study, HWB is strongly influenced by HWA resulting in 6 confirm positions for this group member. Following the AI outcome, HWB confirms the positions of the empowered positioners, HWC and HWD but confirms 0 positions advocated by the stagnant positioner, HWA:

> *HWB:*
> *But some of them like, think they can care for each other.* (Able – 2nd)
>
> *HWA:*
> *But I think she's a bit, I think she's a bit gone for dementia though, because she said that she continues to drive although she now avoids long distance because she feels this is due to her own preference rather than a decline. Is she avoiding the thing that she's declined?* (Dementia unseen -)
>
> *HWD:*
> *She knows though, that, she's d..She knows that her d..That she's a declining..so I don't think her dementia's that far if she knows..you know what I mean?* (Able + 2nd)

> *HWB:*
> *Yeah, 'cause if she knows. If she can feel it in herself that she's like declining then..does that make sense?* (Able + Confirm)

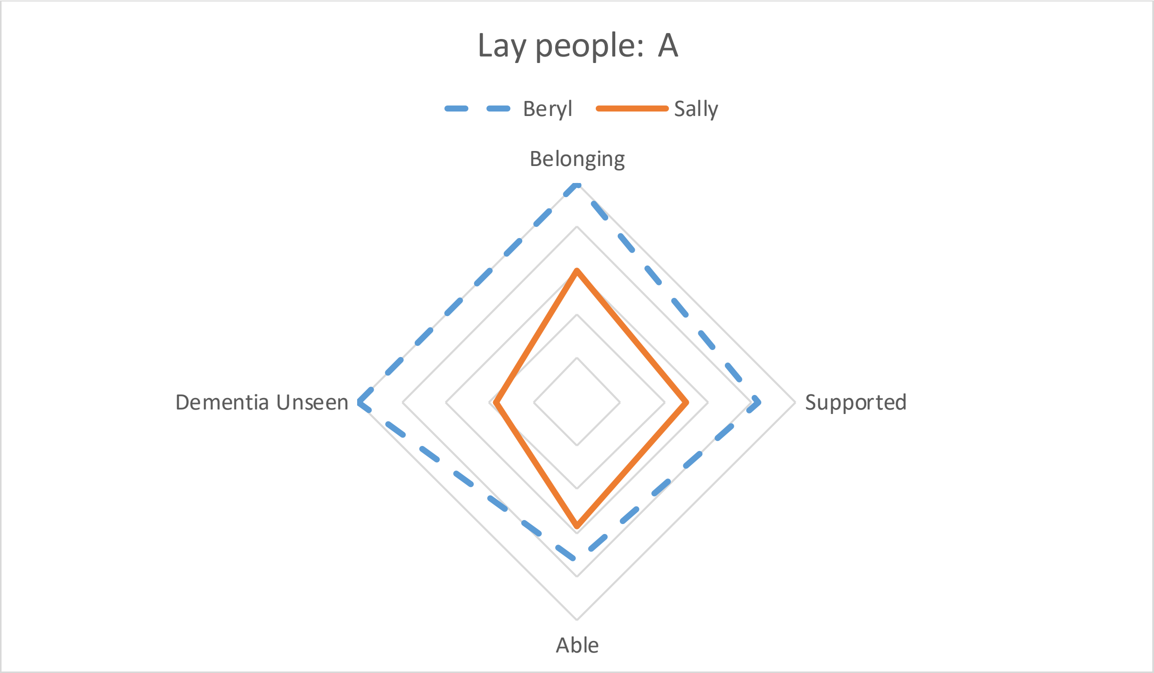
HWB's initial 2nd order challenge creates a negative *Able* position. The negative positioning value is confirmed in the positioning by HWA which is subsequently challenged by HWD's 2nd order. During Beryl's case study, the high number of confirm positions allocated to HWA by HWB indicated a shared understanding. Following the AI outcome, HWB confirms the positive position, illustrating her openness to influence by the AI outcome and the positive positioning allocated by other group members.

HWB's acceptance and confirmation of positive positions, following the AI outcome is not reciprocated by the other group members, with only the reluctant positioner HWG receiving a lower number of confirm positions (2) than HWB (3) during the Sally case study.

Lay people

LPA's Balancing Framework (Figure 40) illustrates increased positive positioning within all four themes.

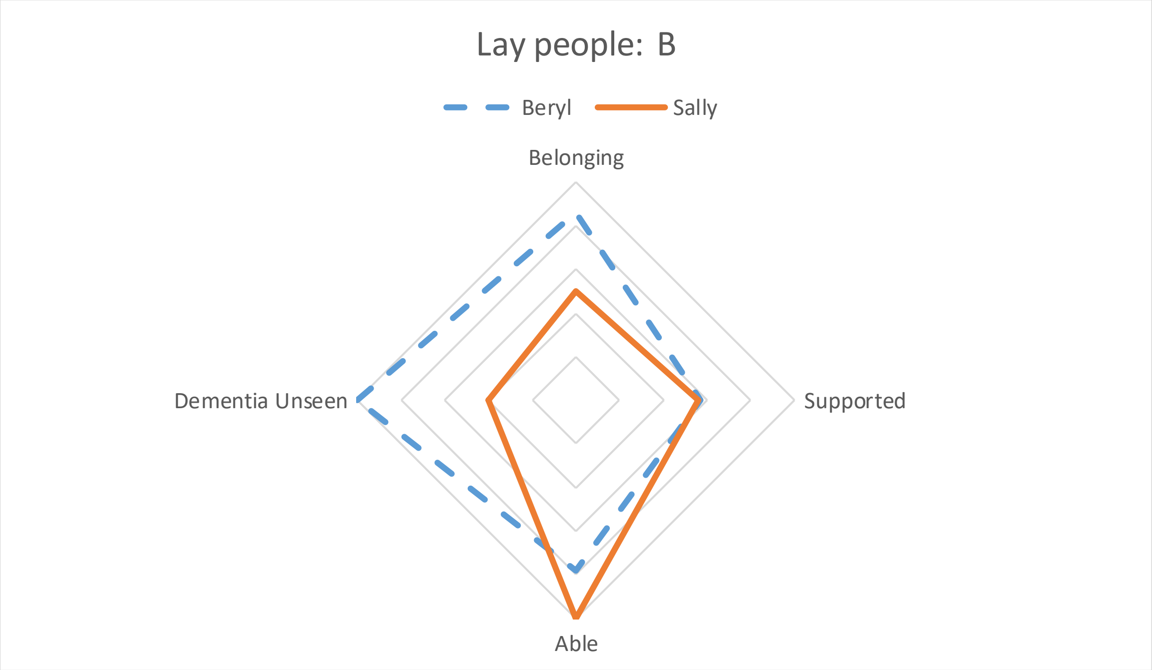
Figure 40: Balancing Framework: LPA



The overall increase in positive positions allocated between case studies (18% to 48%) is indicative of her open positioning. The shift in positivity is also observed in LPA's confirm positions with no positive confirms allocated in Beryl's case study but 5 allocated to Sally's. Negative confirm positions are also reduced (7 to 2). In Beryl's case study, LPA confirms her own positioning on 3 occasions but does not confirm herself during Sally's discourse. LPA's positions were allocated the most confirms by other participants (12), compared to those allocated to other group member's positions, during Beryl's case study. LPD received the second most confirm positions (11), illustrating the esteem, which the practical experience of these two group members was held by other lay people. In Sally's case study, LPA received 8 confirm positions, although the same number was also allocated LPB's positions and the overall allocation of confirm positions within the group was more evenly observed. The movement in confirm positions illustrates the changing narrative as the AI outcome influences the positions allocated to people living with dementia. LPA illustrates her openness to this new narrative, by not attempting to strengthen or confirm her own positions during Sally's discourse. LPA is unafraid to lose the authority her practical experience had provided during Beryl's case study. Whilst LPA offers confirm positions for LPB's discourse consistently through both case studies (3 to 4), her rejection of attempted 2nd orders in this discursive relationship also illustrates the movement to more positive positioning. In Beryl's case study, LPA rejects 2 of LPB's attempted 2nd orders as a means to decrease the positioning value of the discourse. In Sally's case study, LPA rejects 2 of LPB's attempted 2nd orders as a means to increase the positioning value of the discourse.

Despite the decrease in positive positioning allocated to *Able* position's, observed in LPB's Balancing Framework (see Figure 41), the overall evolution of allocated positions following the AI outcome are commensurate with an open positioner status.

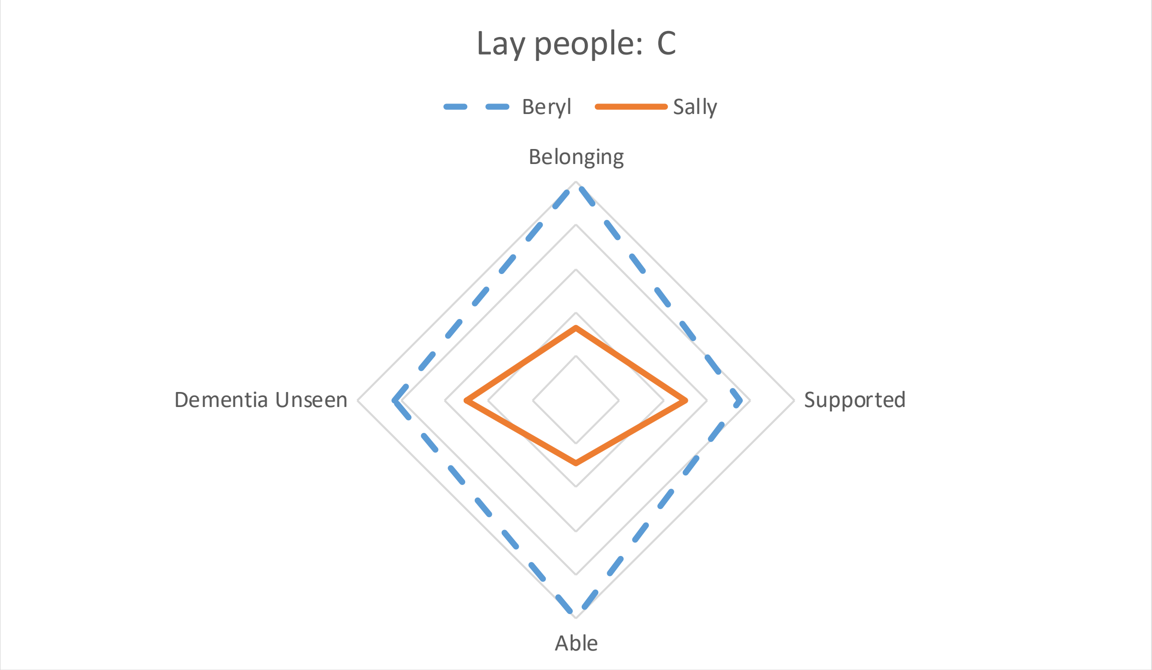
Figure 41: Balancing Framework: LPB



There was a decrease in overall allocated positions between case studies (31 to 22) with an increase in positive positions (16% to 41%). Positive confirm positions were allocated twice in Sally's discourse but were absent in Beryl's. HWB was influenced by the practical experience of LPA during the Beryl case study, allocating 4 confirm positioners to this group member. LPA's influence remains evident in Sally's case study with 3 confirm positions allocated by LPB although the latter participant now confirms their own positions equally (3). The Delivery of the AI outcome results in HWB having more confidence to endorse her own positions.

LPC 's Balancing Framework illustrates increased positive positioning in all thematic areas (see Figure 42)

Figure 42: Balancing Framework: LPC



LPC exhibits a considerable growth in positive positioning between the case studies (6% to 68%). Confirm positions are also observed to change with 6 negative confirm positions allocated during Beryl's case study and an absence of this positioning for Sally's discourse. An absence of positive confirm positions in Beryl alters as 3 positive contributions are observed for Sally's case study. Confirm positions allocated in Beryl's case study are influenced by LPA's practical experience (4) but this influence is diminished following the Delivery of the AI outcome (2). The substantial growth in positive positioning does not indicate a dominant empowered position as LPC's positions are not observed to have a considerable influence on the positioning by other group members. LPC offers few 2nd order positions (2 in each case study) resulting in an open positioner status, which is influenced by others but does not attempt to influence.

The discourse example illustrates the three open positioners in the lay people group's discourse during the Sally case study:

LPA:

Well, that's all..not driving long distance and she feels she can do that.
(Belonging +)

LPC (Lay Person C):

Sounds as though they're in the early stages anyway, aren't they? So, I mean..
(Dementia unseen =)

LPA:

That's enough. When I, I that would be my preference you see. I wouldn't want to go that far. (Dementia unseen + 2nd)

LPB:

No, no. Well, I, I only drive as far as Colwyn Bay. (Dementia unseen + Confirm)

LPA:

Exactly. She's not. It's not because they can't drive. It's, it's just a preference.
(Dementia unseen + Confirm)

LPC:

Yeah, it's a preference so, rather than a decline in her driving abilities.
(Dementia unseen + Confirm)

LPB:

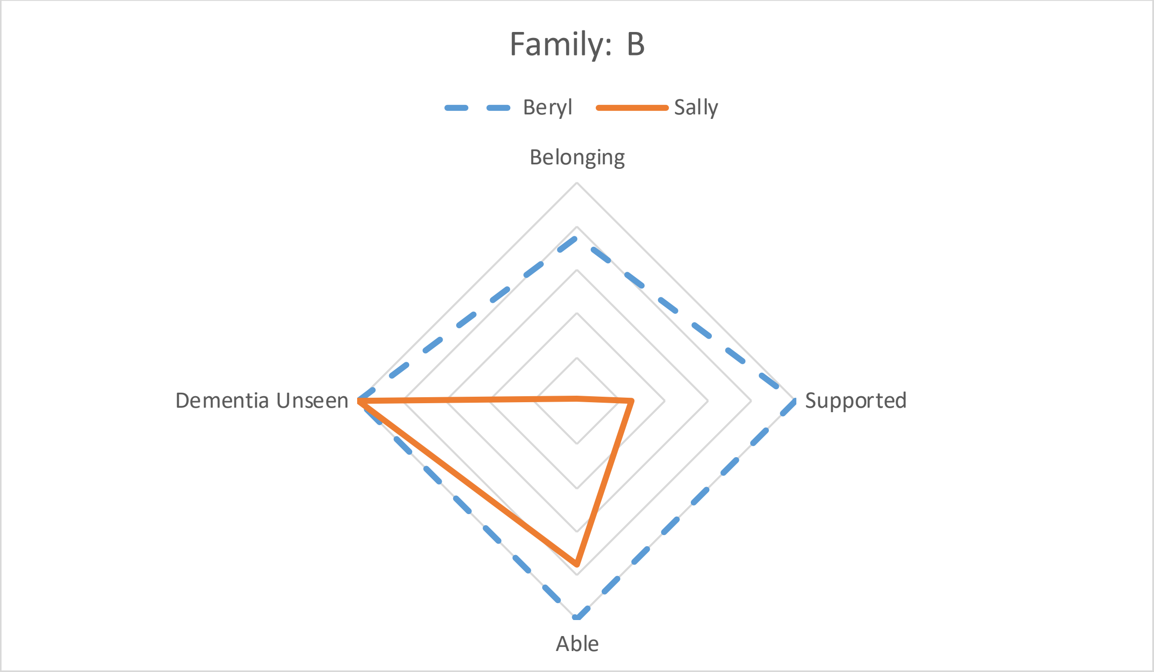
I won't drive to Chester. (Dementia unseen + Confirm)

The open positioners willingly debate Sally's driving behaviour, confirming a positive line of discourse, which concludes with the positive comparison of Sally and the positioner themselves. Sally is not regarded as the 'other' but is compared equally to the group member.

Family members/carers

Dementia Unseen remains, consistent with other participants in the family members/carers group, the only theme to not be positively affected following the delivery of the AI outcome in FB's positioning model (see Figure 43).

Figure 43: Balancing Framework: FB



An overall increase in positive positions occurs in Sally's case study (7% to 50%) although the dominance of Dementia Unseen positions in FB's discourse result in no change in the occurrence of negative positions (50% to 50%). FA's open positioner status is demonstrably ephemeral with its application justified through the positive positioning changes in three thematic themes whilst a stagnant positioner identity is applicable to the *Dementia Unseen* theme. The open positioner identity is further justified as an absence of positive confirm positions is observed in Beryl's case study compared to 2 for Sally. Only 1 negative confirm position is observed in Sally's case study compared to 5 for Beryl. FA does not attempt any 2nd order positions during the discourse concerning Sally's case study and does not attempt to reject any 2nd order positions proposed by other group members. FA illustrates an openness to positive positional change but also remains passive regarding attempts to influence the positioning of other group members.

FA is influenced by the positions allocated by FC, confirming 3 positions for this participant compared to 1 for each other group member during the Sally case study:

> *FB:*
> *Yes, my dad was the same. As if there's nothing behind them is there? It's as if, it's stuck. They look right through you and it's..* (Dementia unseen – Confirm)
>
> *FA:*
> *Yes, see right through and it's quite uncomfortable sometimes.* (Dementia unseen – Confirm)
>
> *FB:*
> *They're trying to works things out, they are? They are trying to work things out, aren't they? It's, it's, there's a look isn't there?* (Dementia unseen – Confirm)

FC:

Well, I see them going absent as if they've not registered what you said. You're talking to them but.. (Dementia unseen – Confirm)

FD:

Vague. (Dementia unseen – Confirm)

FC:

Yes, vague. We better do this, sorry. (Dementia unseen – Confirm)

FD:

Well it's, it really again depends where they are. (Dementia unseen = 2nd)

FC:

There must be a way to support them to live together and you don't want to separate them. (Belonging + 2nd)

FB:

And again it's important that they both continue to play bowls. (Supported +)

FC:

Yes, but again, as she says (points to video) if we say, if we say 'no', we say 'no'. And that's quite difficult because they've made a decision so you can't control them and she doesn't want, she says don't control us if we say 'no', we mean no. (Supported + Confirm)

FC's positive 2nd order positioning is confirmed by FB who is open to this influence. The confirmed negative positioning is strengthened through the agreement of each subsequent speaker until it is neutrally challenged by FD and subsequently positively challenged by FC. The empowered positioner, FC, is confirmed by FB due to her open positioner status as the new narrative is accepted.

The analysis of FB's data over the three levels of Bamberg's (1997) analysis (detailed in 2.4.2) was difficult due to the inconsistency of the results. Level 1 analysis using the Balancing Framework indicated clear positive change in two positioning themes and a smaller degree of positive change in a third. This change was countered by the continued non-positive positioning within the Dementia Unseen theme. The analysis was further complicated due to the large number of positions within this theme, resulting in 50% of positions remaining negative. The level 2 analysis was confused by the lack of 2nd order positions within FB's discourse. For other participants the analysis was often tangled by large data sets with diverse discursive behaviours. When the analysis was discussed with the supervisory team, I was able to share the development of identities in other participants but was concerned by FB's lack of data in level 2. The supervisory team provided reassurance that the analysis was accurate and therefore, if the outcome was unclear compared to other participants, this was a finding in itself and was indicative of the ephemerality observed in positions and positioners in other groups. As the analysis included three levels, this created more data to analyse with each subsequent level. I can now reflect that many of my concerns during these periods were due to my anxiety that I would not reach a satisfactory finding. Whilst I was pleased with the development and outcomes of the Balancing Framework, the outcomes using Bamberg's levels (1997) were less clear from the onset of analysis. For FB, the level 3 analysis was crucial in defining her prominent positioning identity. Once chunks of the transcript were broken into storylines, the disparity between allocated positions across themes became clearer. Discourse concerning the Belonging and Supported themes had evidently become more aligned to the changes advocated in the AI film, indicating an open identity. The lesser changes in discourse concerning ability suggesting a movement between a stagnant and open identity during storylines concerning the Able theme. The lack of change with an absence of 2nd order attempts in discourse concerning the Dementia Unseen theme suggested a stagnant rather than threatened identity within the theme. I was left with four versions of positioning analysis tied to each theme, indicating various positioning identities for FB. In a purely numerical analysis, FB's dominant identity could be equally regarded as open and stagnant but by discussing these outcomes with the supervisory team and returning to the demands of the AI film, the favourable changes observed in the majority of the themes produced a dominant open identity.

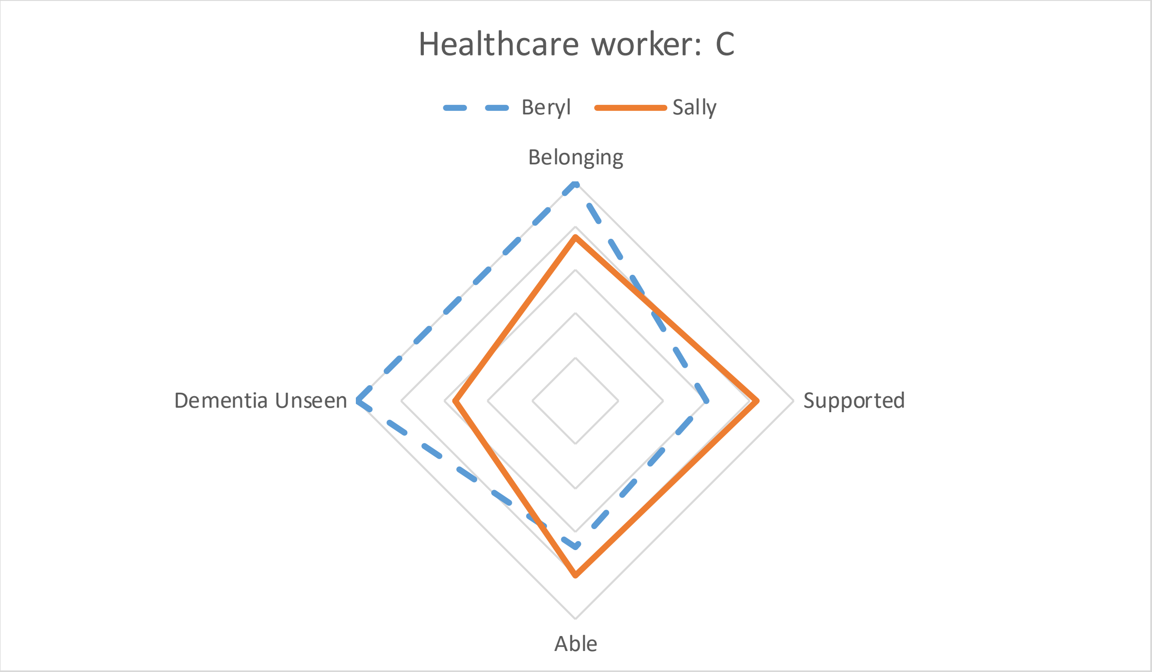
7.4.3 Empowered positioner

This identity indicates a participant who feels that their positioning is enlightened by their experiences and is therefore factually sound. Empowerment may be derived from practical and emotional attachments including the observation of the AI outcome. An empowered positioner affected by the AI outcome is more likely to contribute positive positions compared to other identities. They are more likely to offer 2nd order positions. They can influence the positioning of others but the strength of this influence varies between the societal groups.

Healthcare workers

Although an increase in positive positioning is observed in only two thematic areas on the Balancing Framework (see Figure 44), HWC's positioning behaviour illustrates a dominant empowered positioner identity.

Figure 44: Balancing Framework: HWC



The first indicator of HWC's empowerment is a marked increase in overall positions between case studies (16 to 36). A similar increase is observed in the number of positive positions (4 to 11). The empowered positioner identity is illustrated in HWC's 8 attempted 2nd order positions to increase the positioning value of discourse for Sally. No other group member attempted to improve the positioning value of discourse as frequently as HWC. Her empowerment following the AI outcome is also illustrated in 4 strengthen positions during Sally's case study, indicating a greater belief in her own allocated positions.

HWC challenges the assumptions regarding Sally's husband:

HWC:

No, I agree with what they say, see, although it doesn't actually state that he, he's worse than her. (Dementia unseen = 2nd)

HWC:

So, you can't assume. (Dementia unseen + 2nd)

HWA:

I think he is still.. (Dementia unseen – 2nd)

HWB:

Why? (Dementia unseen + 2nd)

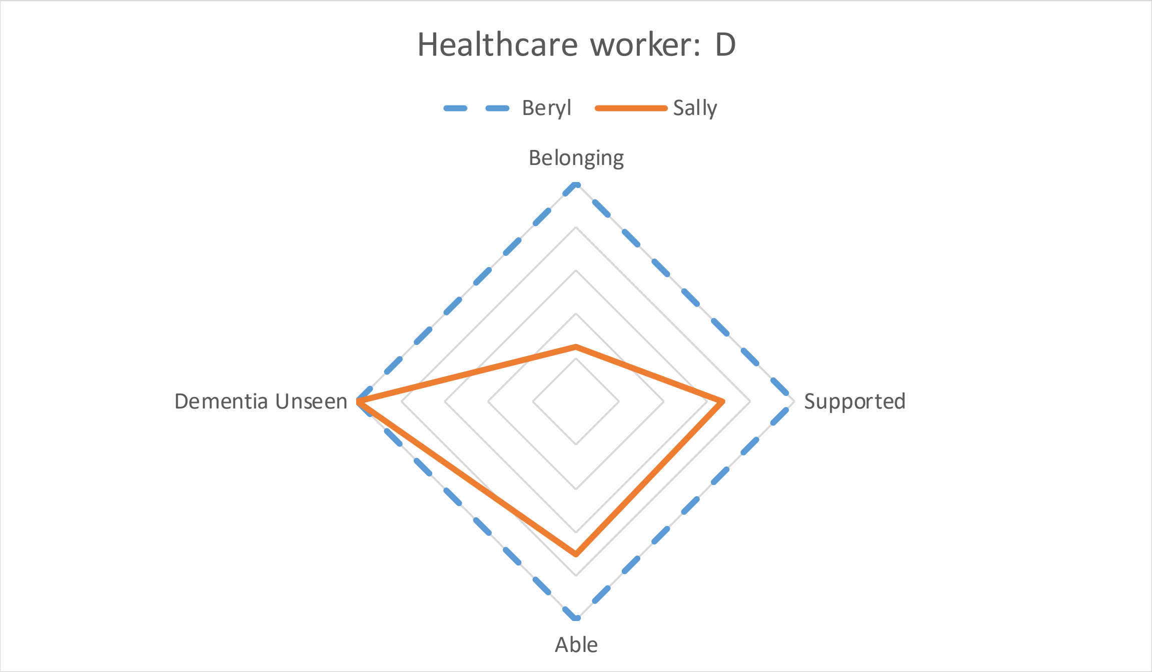
HWC:

You can't assume (name). (Dementia unseen + Confirm)

HWC is empowered to reject the growing negative narrative concerning Sally's husband, informing members of the group that their positioning is based on assumptions rather than factual evidence. The open positioner, HWB, confirms HWC's discourse, allowing a continuation of positive positioning.

HWD's Balancing Framework (see Figure 45) illustrates a growth in positive positioning between the case studies in all four thematic areas.

Figure 45: Balancing Framework: HWD



HWD allocates twice as many overall positions in Sally's case study (8 to 16). HWD allocated no positive positions throughout the entirety of Beryl's case study but following the Delivery of the AI outcome, 44% of allocated positions during Sally's discourse are positive. During Beryl's case study. HWD has a reluctant positioner identity, offering no attempted 2nd orders and 3 confirm positions. Her empowerment following the AI outcome is depicted in 6 attempted 2nd order positions to increase the positioning value of discourse, although the overall increase in confirm positions (7) is commensurate with the increase in overall allocated positions.

HWD's empowered positioner identity is illustrated in the following discourse with HWA, a dominant stagnant positioner:

> *HWA:*
> *Yeah, I think he is to be honest and I think she should like go to the day centre like. She can go with him but it gives her a bit of a break, if he has declined more than her.*
> (Supported = 2nd)
>
> *HWD:*
> *Or if they have a choice, if they go to two day centres or if they want to go together.*
> (Supported + 2nd)

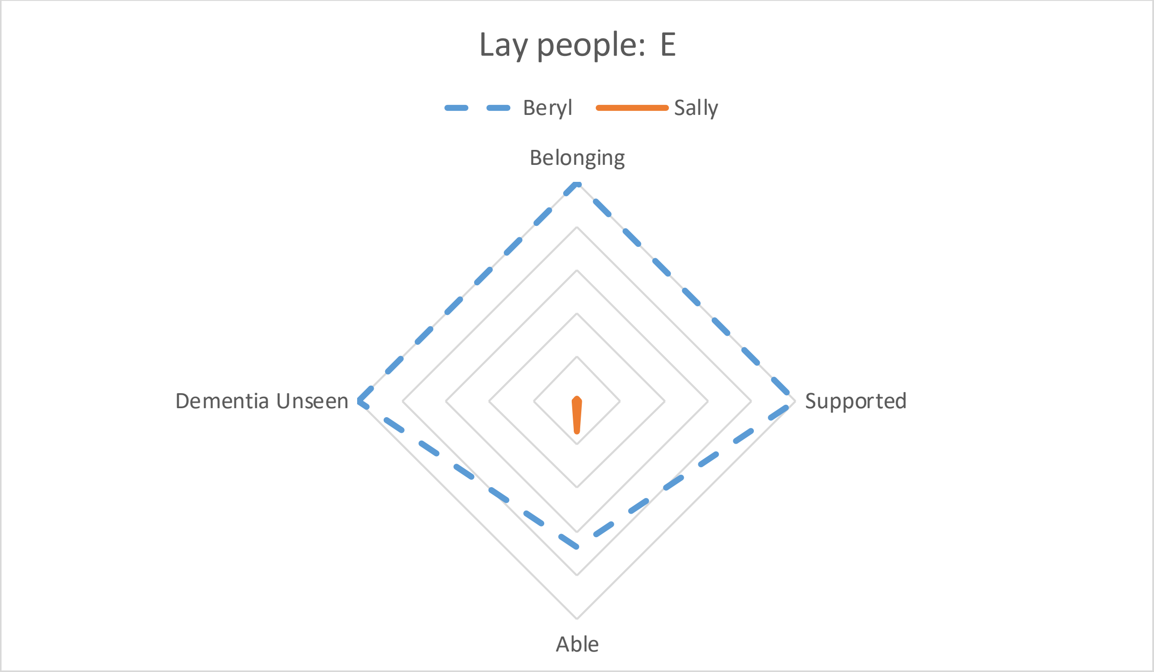
> *HWA:*
> *Yeah if, if she is looking after him then she could do with a break, couldn't she? But..you don't know do you? If she's worse, or..* (Dementia unseen – 2nd)
>
> *HWD:*
> *Depending if she wants a break from him.* (Belonging + 2nd)

HWD, who previously offered no attempted 2nd order positions, is now empowered to challenge the negative positions created by the discourse of other group members. Although, HWA does not confirm the new positive narrative, HWD remains empowered as her own positioning is unaffected by the negative challenges.

Lay people

LPE's Balancing Framework (see Figure 46) indicates this participant allocate positions most closely aligned to the people living with dementia's ideal world.

Figure 46: Balancing Framework: LPE



The growth in the number of overall positions indicates a degree of empowerment following the Delivery of the AI outcome (21 to 38). The increase in positive positioning (10% to 97%) illustrates the impact of the AI outcome on LPE's discourse whilst the empowered identity is observed in the development of her discursive relationships with other members of the group. LPE confirmed 0 positive positions during Beryl's case study whilst confirming 5 for Sally's case study. One 2nd order to decrease the positioning value of discourse was attempted in Beryl's case study whilst there was an absence of this 2nd ordering for Sally. A greater impact is observed in 2nd order attempts to increase the positioning value with 1 attempted allocation for Beryl and 7 for Sally. Whilst LPE confirmed LPD's positions in Beryl's case study (4), the positioning by the same group member was rejected on 4 occasions as LPE remained consistently positive. Both LPA and LPF also had positions rejected by LPE to increase Sally's positioning value.

LPE regularly referred to the AI outcome to justify her allocation of positive positions during Sally's case study:

> *LPE:*
> *And I don't think that they should be separated because as you heard one gentleman say, I, you know, I, and we've seen it with (name), you know, pe.., in experience like. I think that they need to be together because they need to see that, you know.* (Supported +)

Whilst LPE refers to the AI outcome to establish her evidence base for positioning, a practical experience is also alluded to. LPE is empowered to look beyond the case study, using what she has observed through AI and by accepting the validity of her previous experience.

The analysis of LPE's data was relatively straightforward during level 1 and 2 of Bamberg's (1997) model (detailed in 2.4.2). The Balancing Framework clearly illustrated the positive change described in the AI film and level 2 analysis indicated LPE's change in behaviour towards other speakers, offering 2nd order positions to promote positive discourse. Once the transcripts were broken into storylines, the positive change was still evident although the mechanism for change was potentially less evident. Following the AI film, LPE used the film to support her new positioning behaviour but also used age as an indicator for potential competency:

> *LPE:*
> *And, and again we don't know how young they are. Remember, we were assuming Beryl was a lot older than Sally. Listening to them, a lot, they were living perfectly normal lives.* (Dementia unseen +)

In this discourse the AI film is referenced to support the position that people living with dementia can live 'normal' lives. However, the ability to do this, is potentially tied to their age, with Sally regarded as more able than Beryl due to her perceived younger age. The people living with dementia in the AI film would all be classified as younger people in the context of the syndrome. Whilst LPE draws on the AI participant's lives, rather than their age to support her position, it is unclear whether LPE still considers an older person living with dementia to be less able to live a 'normal life'. Whilst the analysis of these storylines during level 3 indicated a potential influence on LPE's positioning of older and younger people living with dementia, similar discourse was not observed in the level 3 analysis of other lay people. LPF was the only other lay person who used age to support a position:

LPF:

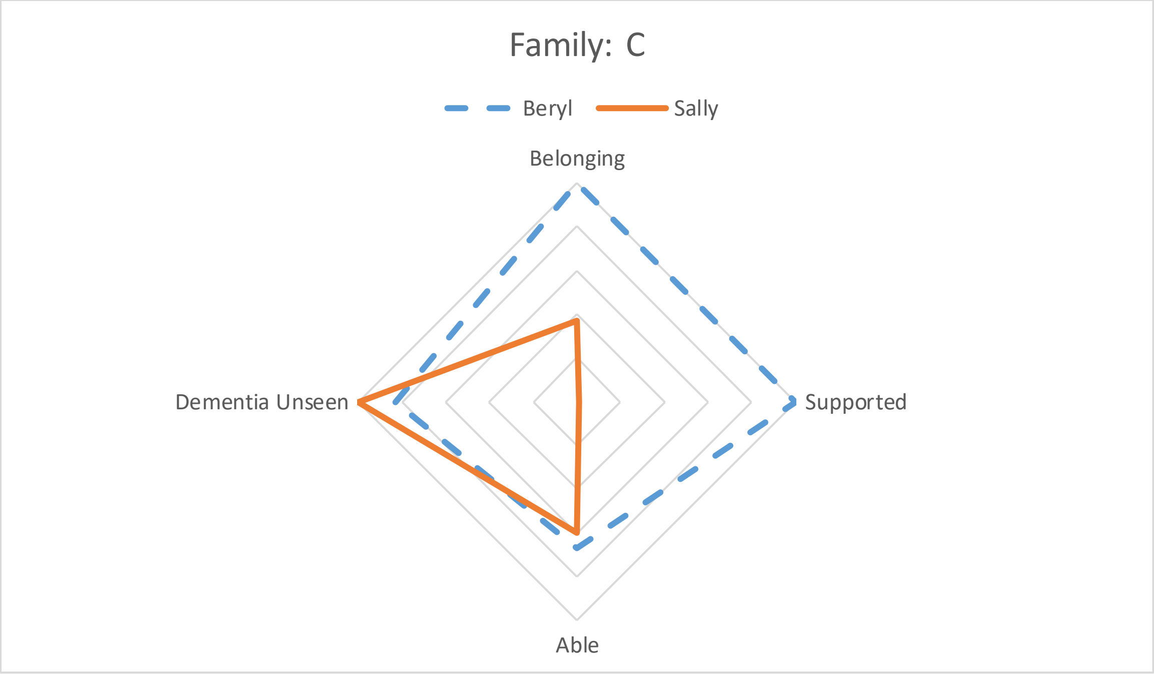
Well, there are a lot of people as they get older.. (Dementia unseen +)

In this discourse, however, older age was not regarded as a negative factor in a person's ability to make competent decisions but to positively view the actions of any person living with dementia. Whilst LPE's analysis was discussed with the supervisory team, the significant positive change in her positioning continued to support her dominant empowered identity despite the potential influence of both the AI film and the ages of the participants living with dementia.

Family members/carers

Similar to other family member/carer participants there is no positive growth in Dementia Unseen positioning for FC. The Balancing Framework (see Figure 47) does illustrate positive change in the other three thematic areas.

Figure 47: Balancing Framework: FC



Empowerment is observed in the overall increased number of positions between case studies (14 to 34). There is an increase in positive positioning (14% to 53%) which is also observed in an increase in positive confirm positions (0 to 4). The dominance of the *Dementia Unseen* theme in this groups, including FC's, positioning illustrates an opposing threatened identity as 2 negative confirm positions in Beryl increase to 10 for Sally, prioritised to this theme. FC's empowerment is confirmed by other members of the group who offer confirm positions for her discourse on 3 occasions in Beryl's case study, which increase to 14 confirm positions for Sally.

The conflict between thematically allocated positioning values by FC is observed in the following discourse:

> *FC:*
> *But again it's really difficult because we've seen four there on the video that can live independently.* (Able + 2nd)
> *FD:*
> *Which one of those do you think was better of the four? Which one was the best?* (Dementia unseen – 2nd)
> *FD:*
> *I think the man was best. Not the RAF, the other one. The one that worked in (site).* (Dementia unseen – Confirm)
> *FC:*
> *But he was repeating himself quite a bit, wasn't he?* (Dementia unseen – Confirm)
> *FD:*
> *Yeah. I saw him the best out of the four.* (Dementia unseen – Confirm)
> *FB:*
> *But he was younger wasn't he? About forty-six. He was very young then.*
> *FC:*
> *Yes, yes. I had a bit of panics.*
>
> *FD:*
> *That's not long to go. He came out better than the others to me.* (Dementia unseen – Confirm)
> *FC:*
> *They all had different strengths.* (Supported + 2nd)

FC's allocation of a positive position related to the *Able* theme is countered by a debate, which group members discuss the people living with dementia's dementia as their defining characteristic. This negative positioning is countered by FC who reminds the group of the people living with dementia's strengths. When discourse does not involve *Dementia Unseen* positions, FC leads the group's positive positioning, but a positive *Dementia Unseen* discourse remains undeveloped, betraying FC's otherwise dominant empowered positioner identity.

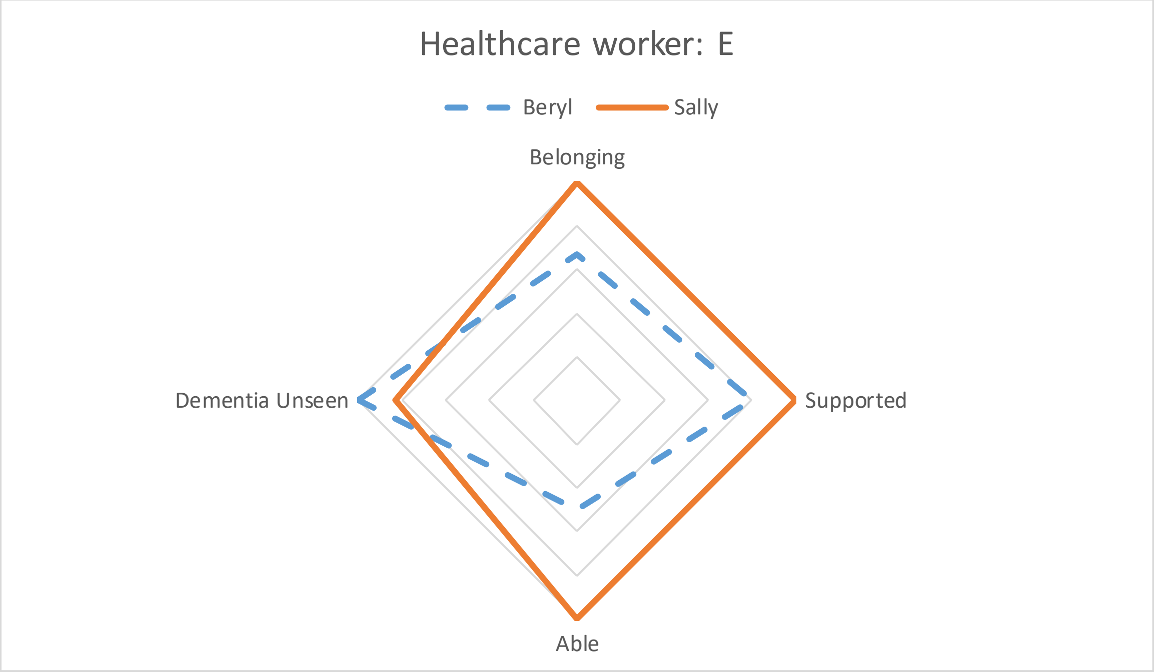
7.4.4 Threatened positioner

This identity is observed in participant's with either practical or emotional attachment that may have previously granted them discursive power over other group members. When new opposing narratives are introduced, the threatened positioner will use their previous experience as a mechanism to counter new ideas. They are likely to lose any influence they had previously on the positioning by open and empowered positioners but may retain their power on stagnant and reluctant positioners.

Healthcare workers

HWE's Balancing Framework (see Figure 48) illustrates a decline in positive positioning within three of the thematic areas.

Figure 48: Balancing Framework: HWE



An overall increase in allocated positions (13 to 23) is observed alongside a decrease in allocated positive positions (31% to 4%). No positive confirm positions are allocated in either case study whilst more negative confirm positions are observed in Sally (4) compared to Beryl's case study (1). Only three 2nd order positions are attempted in Sally's case study (2 to decrease positioning value) illustrating that HWE does not wish to directly challenge the increasingly positive discourse but does offer negative discourse when it concurs with current narratives. HWE's awareness of increased positivity and the movement of the group towards this positioning value is illustrated in the following discourse:

> *HWE:*
> *Well I think like short journeys is fine, erm, because it is all about that positive risk taking. There not, like, we're not to take pity on them, they have still got that like, capacity and capability to do it. We shouldn't treat them any different because they have got a diagnosis so I think that's fine (laughs). (Dementia unseen +)*
>
> *HWD:*
> *And she might know when to actually give up her driving licence 'cause she's done it from so far away so when she feels like she can't cope.. (Able +)*
>
> *HWF:*
> *But I wonder why she now avoids long distances, why she suddenly thought, I can't do that anymore. Has something happened to make her think she can't do it?*
> *(Dementia unseen – 2nd)*

HWE:
I don’t want her in my group, can I move her over there?

(B and E laugh)
HWF:
Hey? You want me to go over there?

HWA:
(nods)

HWE verbally rejects HWF, who is regarded as offering positions, which oppose the new narrative following the AI outcome. HWE directly refers to the AI outcome when allocating a positive position but the rejection of HWF contradicts the remaining positions allocated by HWE. Whilst HWF’s dominant stagnant identity is informed by the unchanging allocation of positions between case studies, HWE’s threatened identity is observed in the increased allocation of negative positions as a mechanism to counter the increased positive positioning by other group members. As the most practically experienced member of the group, HWE is threatened by the new positive discourse and uses negative positioning as a mechanism to re-establish her authority.

HWE introduces the discourse, to suggest Sally’s husband is a negative factor in Sally’s life:

HWE:
But does she want to be, just be closer to home because her husband’s so bad? (Belonging –)

HWF:
And how do you know that?

HWC:
You’re making a lot of assumptions. (Belonging+ 2nd)

HWD:
It doesn’t say.. (Belonging + Confirm)

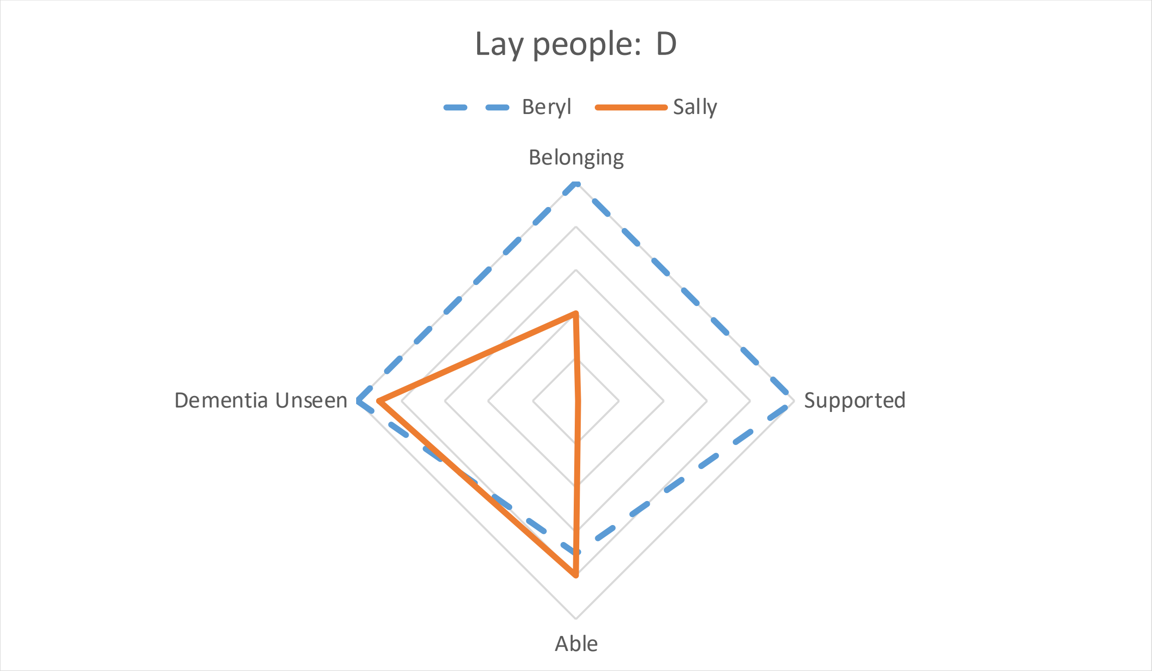
The assumptions regarding Sally’s husband are countered by other group members unwilling to confirm HWE’s negative discourse, following the AI outcome.

Data analysis using Bamberg’s (1997) levels is described in 2.4.3. The level 1 analysis incorporated the results of the Balancing Framework, which illustrated less positive positioning in three of the four domains. Whilst this indicated that the AI film had not produced the desired effect on HWE’s discourse this was countered by the relational discourse at level 1, when HWE criticised HWF’s negative positioning. This created conflicting data with HWE seemingly aware of the more positive discourse being presented through the AI film but actually producing more negative positions through her own discourse. Kitwood (1997) described malignant social psychology as behaviours, which are often made by people unaware of their malignancy. In this analysis, the results were less clear as HWE expressed an awareness of positive positioning despite an increase in offering negative positions. I attempted to map the positions in the Balancing Framework to the demographic data of the participants to illustrate their relationships, using Max Weber's (1864 - 1924) (Gerth, Mills & Turner, 2013) descriptions of power, with HWE allocated traditional authority due to her role as a senior carer and having the longest employment history at the home. However, this approach created tensions as the allocations of authority were based on assumptions due to the demographic data. This analysis was therefore discontinued prior to moving to level 2. The level 2 analysis reduced the discourse to occurrences of positioning behaviours (e.g. 2nd orders, confirmatory positions), which whilst revealing was also complicated as the numerical occurrences required constant alignment with the actual discourse to ensure the storyline being analysed was not reduced to numerical data only. The analysis at this level suggested that HWE did not tend to influence others following the AI film, supporting the discontinuation of using assumed authority as a mechanism for analysis, but supported negative discourse more regularly. During level 3 analysis the transcripts were broken into chunks of connecting storylines. For many participants the presentation of themselves matched the changes or lack of changes in their positioning of people living with dementia. HWE's analysis was complicated due to the disparity between how she positioned herself (by aligning her actions to the positivity of the film) whilst offering more negative positions. However, this disparity, also evident in the analysis of LPD, informed the development of an overall threatened positioning identity. During supervision, positioning identities were discussed and evolved, with both participants allocated to a closed identity (which was further refined into the stagnant identity). Through the complex analysis over the three levels, the disparity between how HWE attempted to present herself within the relational discourse of the group and her actual positioning of people living with dementia informed the allocation of a threatened identity.

Lay people

Although the Balancing Framework (see Figure 49) indicates increased positive positioning in three thematic areas (Belonging, Supported, Dementia Unseen), the threatened positioner identity is observed in LPD's altered discursive relationship with other group members following the Delivery of the AI outcome.

Figure 49: Balancing Framework: LPD



A minor increase in overall positioning is observed between case studies (20 to 23) alongside an increase in positive positioning (15% to 39%). The positive increase is countered by an increase in negative positioning (45% to 52%). LPD is the only group member to allocate more negative positions following the observation of the AI outcome. LPD's practical experience informs her position as having the most confirm positions allocated to her discourse in Beryl (11) which inspires her confidence to confirm her own positions on 4 occasions. During the Beryl case study, LPD's dominant positioning identity is aligned to the empowered positioner. The AI outcome is used by all group members to inform their positioning during Sally's case study, reducing the impact of LPD's practical experience. Whilst other participants her positions to a lesser degree (7), LPD rejects 2nd order positions with greater regularity in Sally's discourse. In Beryl's case study LPD attempt two 2nd order positions, equally representing discourse to increase and decrease the positioning value. In Sally's case study, six 2nd order positions are attempted, with 5 attempting to decrease the positioning value. LPD rejects 4 of LPE's attempted 2nd order positions to increase the positioning value, illustrating the change in the discursive relationship between the two members, who had offered an equally high number of confirm positions to each other's discourse during Beryl's case study (4).

The discursive relationship between LPD and other group members during the Beryl case study is illustrated in the following discourse:

LPD:

We didn't think it was safe enough for her to be alone. (Able -)

LPF:

No, we didn't think it was safe enough. (Able – Confirm)

LPD:

With, but she could with further care. (Supported = 2nd)

LPE:

With further care. (Supported = Confirm)

Other group members accept LPD's practical experience, which empowers her to influence the positions by them. As LPD offers new positioning values, the other group members confirm them through their own discourse.

The discursive relationship between LPD and other group members during the Sally case study is illustrated in the following discourse:

LPD:

We have to say, don't we, straight away that no, we don't think they should be on their own? There should be some support, shouldn't there? (Able -)

LPE:

No, They'll be fine. At least, no, I still don't think they need it because (gestures towards TV) they could be young couple and the, there's, people we just looked at. (Able + 2nd)

LPD:

Yeah, she's got someone to call if, but..

LPE:

Cope with. She's not on medication is she?

LPD:

But would they realise that they needed help and call that? You know, They've got a telephone number to ring if they need help in the future. (Able = 2nd)

LPF:

They're saying, they both regularly attend church, so they're obv..

LPE:

They've been in touch with services.

LPD:

You'd hope that
somebody would..

LPF:

So, obviously they're still part of the community, aren't they? (Belonging + 2nd)

> *LPE:*
> *And, and again we don't know how young they are. Remember, we were assuming Beryl was a lot older than Sally. Listening to them, a lot, they were living perfectly normal lives.* (Dementia unseen +)

LPD's positioning values are rejected by the other group members. The empowered positioner LPE is no longer influenced by the practical experience of LPD who offers less positive positions, aligned to those more frequently observed during Beryl's narrative, as a mechanism to re-establish her discursive influence over the other group members.

Family members/carers

The threatened positioner identity is not dominant in any of the four family member/carer group members. It does, however, dominate all four members positioning related to the *Dementia Unseen* position. Two members of the group continue to offer no positive *Dementia Unseen* positions following the AI outcome whilst FC decreases positive positioning within the theme from 17% to 0%. Only FD increased their allocation of positive *Dementia Unseen* positions, although the effect is minimal (0% to 8%).

The practical experience of having a relative who has entered the final stages of their dementia opposes the practical experience of the people living with dementia who share their demands in the AI outcome. The group use their own experiences to position the people living with dementia featured in the AI outcome by their dementia symptoms:

> *FD:*
> *And then I was saying to them, of the four that I saw I thought the man who was fifty-six looked better than the others, was coming out, speaking better. The one that worked in the fair, yes? (Dementia unseen – 2nd)*
>
> *FC:*
> *Well, I didn't agree with you, did I? (Dementia unseen – Confirm)*
>
> *FD:*
> *But I saw this one. I thought, well he looks better than the others, somehow, myself. (Dementia unseen – Confirm)*
> *FC:*
> *But then he didn't want to hear that he didn't, that he did look better.*
>
> *FD:*
> *No, he didn't want to hear. But for myself I wouldn't have known that he had Alzheimer's. (Dementia unseen – Confirm)*
>
> *FA:*
> *The way I see them, I was saying earlier, the way that Mum would just look and my partner's father as well. The way they look at you, blank, as such. They stare at you but they're totally blank. Maybe, trying to suss something out. There's a, a look*

> *about their eyes, isn't there? And I've had it with quite a few people, noticed afterwards, after seeing it. (Belonging -)*

LPA's reference to her mother to suggest that people living with dementia are '*totally blank'* does not correspond with the growth of positive positions by this group in other thematic areas. Whilst other thematic areas are more readily accessible to this group for positive positioning, *Dementia Unseen* creates an immediate challenge to their emotional attachment, illustrated by the lack of positive positioning and the threatened identity within the theme.

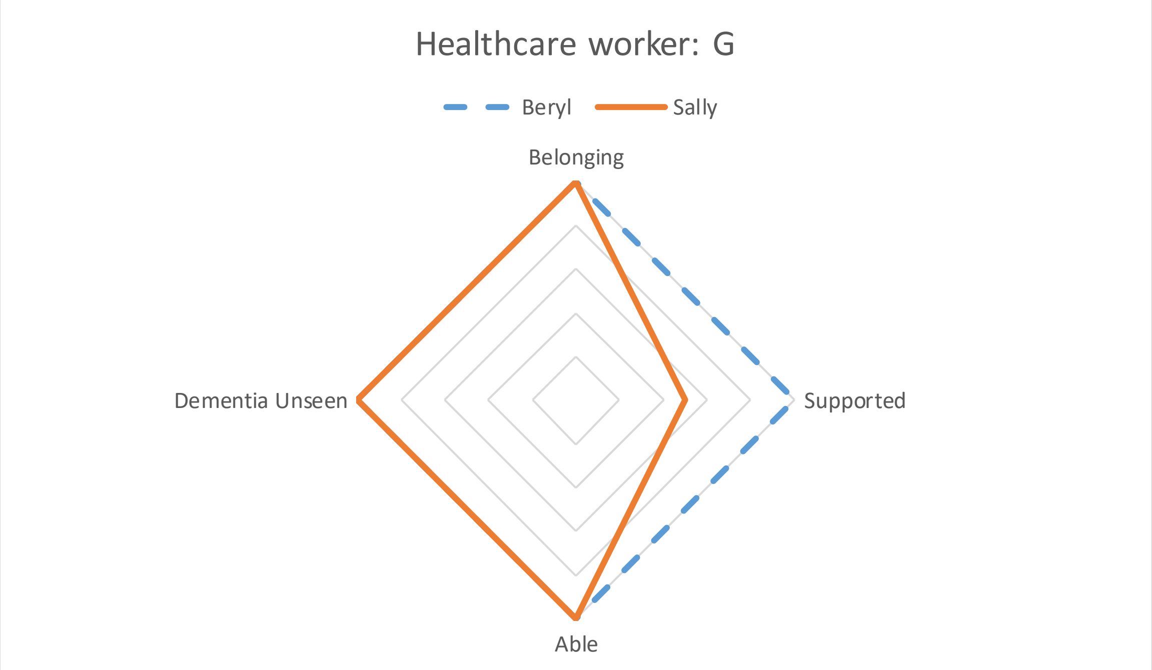
7.4.5 Reluctant positioner

This identity offers fewer allocated positions than other identities. Confirm positions will be commonly offered whilst 2nd order positions are typically consistent with other group member's previously offered positions. Reluctant positioners rarely influence the positioning of other group members but are readily influenced themselves. The identity of the reluctant positioner may be unclear due to the limited number of allocated positions offered.

Healthcare workers

Although HWG's overall allocated positions doubled between the case studies (3 to 6), there was minimal change to the Balancing Framework (see Figure 50)

Figure 50: Balancing Framework: HWG

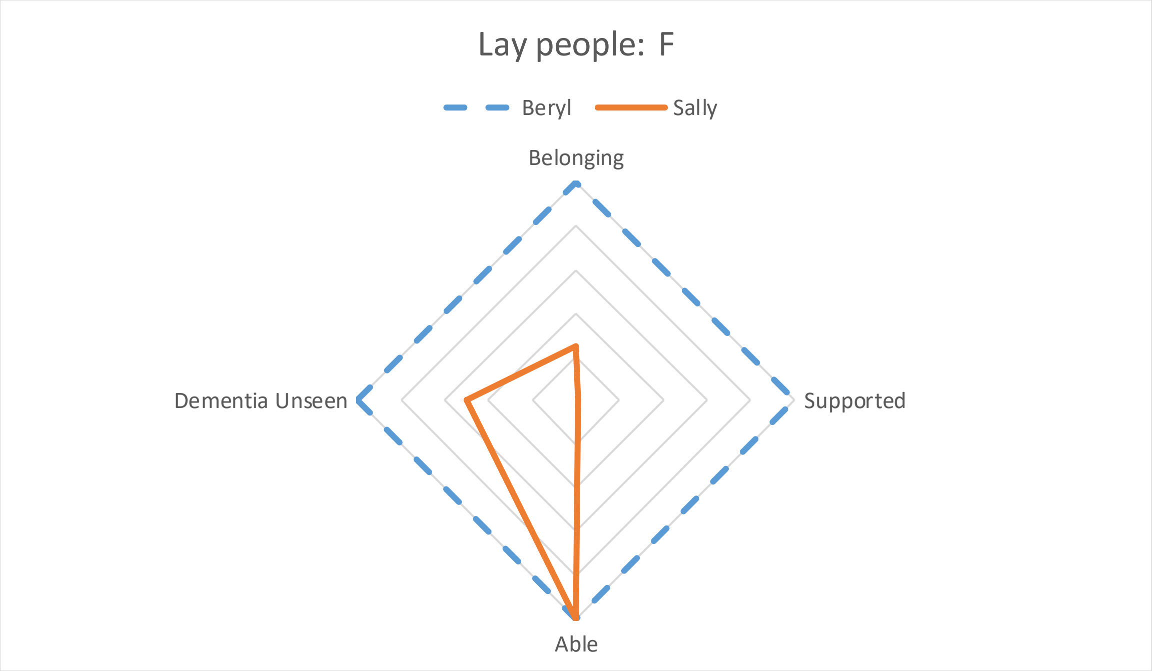


No 2nd order positions are attempted in Beryl's case study and although 2 are attempted in Sally's discourse, both offering negative positions. Although the dominant identity is a reluctant positioner, there are attributes of a stagnant positioner also evident. HWG's proposes the use of a virtual reality driving experience for Sally, comparable to the virtual shopping experience proposed in Beryl's case study. This suggestion illustrates that HWG's positioning of people living with dementia overall has been unaffected by the AI outcome. She confirms two positions in the Sally case study, one originally allocated by HWF (a stagnant positioner) and the other, HWE (a threatened positioner but on who holds the most practical experience, opposed to HWG with the least). The increased number of positive positions (0 to 1) does not suggest a shift in HWG's positioning of people living with dementia, although due to her reluctant positioner status she offers little insight into her positioning identity.

Lay people

With the exception of the Able theme there is observable increased positive positioning in LPF's Balancing Framework (see Figure 51). The reluctant positioner identity is informed by the significant decrease in allocated positions following the AI outcome (21 to 8).

Figure 51: Balancing Framework: LPF



The positioning values offered by LPF in Sally's case study, when considered in isolation, are aligned to an open positioner identity. There is a marked increase in positive positioning (5% to 63%) whilst only negative confirm positions are offered for Beryl (3) compared to only positive confirm positions for Sally (3). The reluctant positioner identity is informed by LPF's discursive behaviour following the AI outcome. In both case studies LPF attempts the least amount of 2nd order positions (3 to 1). During Beryl's case study, LPF aligns her positioning to group members with emotional and practical experience:

LPD:

I don't think she should be on her own, do you? (Belonging =)

LPF:

No, I think, I think that ten minutes, ten minutes is actually not a long time. (Supported =)

Following the AI outcome, LPF allocates positions which acknowledge the increased positivity in the discourse:

LPD:

She drives.

LPE:

Yeah. So, she certainly hasn't deteriorated. (Supported +)

LPF:

So, that's a form of independence, isn't it? (Supported + Confirm)

LPF contributes to the new narrative but is reluctant to offer positions independently through 2nd orders or counterpoints to 2nd orders attempted by other speakers. The increase in positive positioning cannot be accurately attributed to the influence of the AI outcome or LPF's susceptibility to follow the majority's group narrative.

Family members/carers

The reluctant positioner identity was not observed in the discourse involving family members/carers. Three members allocated a greater number of overall positions following the Delivery of the AI outcome whilst HWB experienced a small decrease (14 to 12). The family member/carers group was notable for the lack of 2nd order positioning. The minimal amount of 2nd order positions allowed participants to share their positions with few challenges, negating the potential of participants becoming reluctant positioners.

7.5 Summary

Pre-existing experiences and relationships guide the discourse about people living with dementia. The AI film created by people living with dementia introduces a further influence on this discourse. The AI film's ability to influence the discourse of individuals can be supported or prevented by their pre-existing experiences and relationships although no positioning identities are observed to be fixed, but ephemeral similar to the allocation of positions within discourse.

The Delivery phase of AI resulted in an overall change in the positioning of people living with dementia within all three societal groups, positively aligned to the outcome of the Discovery, Dream and Design phases, as described in chapter 5. This chapter explored this change further, describing the factors, which indicated individual participant's susceptibility to the influence of the AI outcome on their verbal positioning of people living with dementia.

Practical experience was demonstrably influential on the positions allocated by the healthcare worker group and to a lesser extent, the positioning by family members/carers. The practical experience of lay people was markedly dependent on individuals within the group, with those noted to have greater practical experience having an observable influence on the positioning of people living with dementia by other lay people.

Emotional attachment was demonstrably influential on the positions allocated by the family members/carers group. The presence of emotional attachment in the healthcare worker group was limited and did not influence the group's positioning of people living with dementia.

Positioning identities, similar to allocated positions, were acknowledged as ephemeral, with dominant identities allocated to participants related to the results of their Balancing Framework and discursive behaviour. Positioning identities were described regarding their susceptibility to the influence of the AI Delivery, positioning by others and emotional/practical experience on individual participant's verbal positioning of people living with dementia.

Chapter 8

Synthesis of Findings

8.0 Introduction

This chapter brings together the findings from the previous chapters to consider their meaning when applied together. The synthesis presented in this chapter considers the process of positioning as a journey from the speaker, the spoken words to the positioned person/people living with dementia.

The research questions for this thesis as presented in chapter 1 were:

- Can AI support people living with dementia to define a lived experience of ideal verbal positioning by others?
- Can the outcomes of an AI cycle with people living with dementia influence the verbal positioning of other groups in society?
- What factors influence the verbal positioning of people living with dementia by members of society aware of the AI outcome?

From the data analysis completed during this thesis, four key conceptual findings emerged and were described as:

1. People living with dementia are empowered to identify the requirements for positive verbal positioning using the Discovery, Dream and Design phases of AI.
2. Four positioning themes as a framework to assess how people living with dementia experience verbal positioning by others.
3. Verbal positions that are directly influenced by the outcomes of AI.
4. Five thematic positioning identities as facilitators and barriers to positive verbal positioning as defined by AI.

The synthesis will be presented through the illustration of three frameworks. One Balancing Framework is presented to illustrate the influences on allocating positions for positioners and another Balancing Framework is presented to illustrate the influences on accepting positions for people living with dementia. A third framework is used to illustrate the journey of discourse as influencers defined in the findings guide the allocation of a position.

The three illustrated frameworks presented are:

- The relation of influential factors to the Balancing Framework.

A framework aligning the Balancing Framework tool and the included thematic positions with the influences of individual positioning described in chapter 7 (practical experience, emotional attachment and positioning identities).

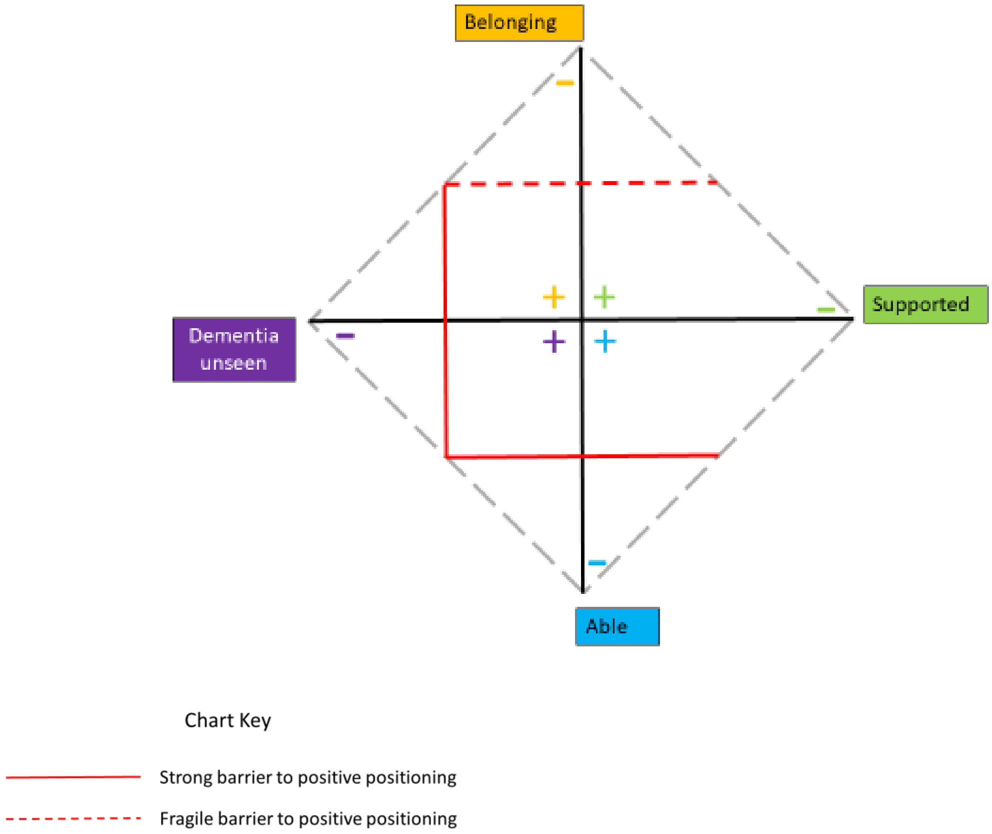
- People living with dementia's experience of the Balancing Framework.
  A framework aligning the Balancing Framework tool and the included thematic positions with the conceptual internal requirements of people living with dementia (abilities used, emotional need and empowered).

- Narrative statement framework.
  A framework illustrating the barriers and facilitators for the positive positioning of people living with dementia, respective of the positioning identity of the person voicing the narrative statement and the allocated positioning theme. The synthesis directly bridges the outcomes of the Delivery phase back to Discovery, illustrating how the AI process has produced a unified framework derived from disparate participant groups in divergent AI phases.

The chapter will conclude with the interconnectivity of the two Balancing Frameworks and narrative statement framework presented as a dynamic process of discourse activity informed by AI. The final integrated model endorses the ability of people living with dementia to influence the positioning of other members of society through AI, whilst acknowledging that the individual experience of positioning is dependent on dynamic forces both external and internal to the person living with dementia and the positioner.

The chapter presents visual representations of the identified factors and their relationship with the Balancing Framework. Figure 52 is shown here as an example to illustrate how this relationship is illustrated. The relationship between emotional attachment and the Balancing Framework is illustrated by the red lines inside the framework. Positive positioning is represented by the centre of the framework and therefore the red lines represent a potential barrier to reaching this centre. The absence of a red line for the Supported theme illustrates that emotional attachment is not a barrier to allocating positive positions within this theme. The dashed red line for the Belonging theme illustrates that although emotional attachment may have prevented participants from allocating positive positions within the theme, the results were inconsistent, suggesting that the barrier is fragile. The unbroken red lines observed for the Dementia Unseen and Able themes illustrate a strong barrier to achieving positive positioning within these themes when emotional attachment influences the positioner.

Figure 52: Balancing Framework: Emotional attachment



8.1 The relation of influential factors to the Balancing Framework

A total of seventeen participants in three societal groups engaged with the case study discussions and the Delivery of the AI outcome. The AI outcome directed participants to allocate positions to people living with dementia regarded as positive by the four people living with dementia who had engaged with three previous AI phases. The Balancing Framework, informed by the first three AI phases, allows the visual presentation of positive positions with desirable positioning located at the centre of the framework. The AI outcome during Delivery was observed to have an overall positive contribution to the positioning of people living with dementia within the societal groups although individual participants varied in their susceptibility to the influence of the AI outcome. A triad of influencers external of the AI process were presented as informants for the positional discourse of individual participants. The three influencers, presented as emotional attachment, practical experience and positioning identities were recognised to be experientially different between societal groups and between individual members within each group.

The variance of impact on the positioning of people living with dementia by participants following Delivery is illustrated in a comparison of the Balancing Frameworks of HWE and LPE. HWE has six years of practical experience in dementia care, is currently employed as a senior carer at a home for people living with dementia and following Delivery, holds a dominant threatened positioner identity. LPE does not declare any emotional or practical experience prior to observing the AI outcome and evolves into an empowered positioner following Delivery. Following Delivery, HWE allocates 23 positions to people living with dementia during the Sally case study with 4% of these positions positively contributing to her Balancing Framework. LPE allocates 39 positions to people living with dementia during the Sally case study following Delivery, with 97% of these positions positively contributing to her Balancing Framework.

Whilst the Balancing Framework visually illustrates the positioning value of the thematic areas identified through AI, it does not stand in isolation from these other influential factors. The outcomes of the three social groups within these influential factors will now be analysed to present a synthesised Balancing Framework incorporating these influencers.

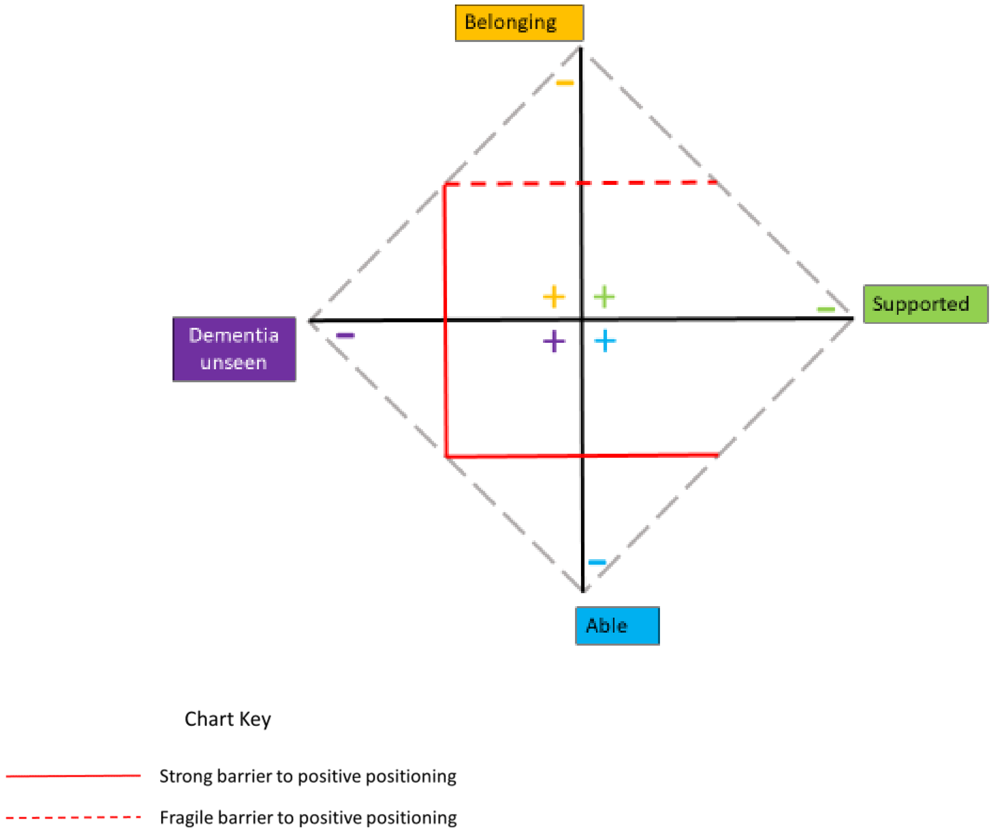
8.1.1 Emotional attachment

The influence of emotional attachment on the positioning by healthcare workers was negligible in both case studies. LPD disclosed the greatest degree of emotional attachment of the lay people group, referring to her father, who had lived in warden-controlled accommodation, to inform her positioning during Beryl's case study. The emotional attachment continues to inform her positioning during the Sally case study, acting as a barrier in two positioning themes, *Able* and *Dementia Unseen*. Increased positive positioning is observed in the *Supported* and *Belonging* themes. *Supported* positions are informed through the *Purpose* sub-theme as LPD aligns her discourse to the people living with dementia in the AI outcome. The *Respect* sub-theme positively informs *Belonging* positions, with LPD referring to the equality between Colin and his wife. The decrease in positive *Able* positioning is aligned to her father's situation as LPD positions him as incapable which is used to inform her positioning of people living with dementia during both case studies. LPB is the only other lay people group member to allocate less positive *Able* positions following Delivery, although these tend to be neutral positions denoting the people living with dementia's possible need for assistance rather than exclusively negative positions. Whilst the positive impact of Delivery on *Dementia Unseen* positions was observed in other lay people group members, the effect on LPD's positioning was minimal with 0% positive positions for this theme allocated in Beryl's case study, developing to 10% in Sally's. Negatively regarded emotional attachments are invoked as LPD positions her father, without dementia, as incapable, resulting in people living with dementia being positioned as inevitably 'worse' due to their diagnosis, informing negative *Dementia Unseen* positioning.

The effect of emotional attachment of the family member/carer group corresponds to the positioning by LPD. *Supported* positions are similarly positively affected with 93% of positions allocated within this theme having a positive positioning value. Emotional attachment acts as a facilitator to positive positioning within this theme as participants responses are built from the experiences of their relatives need for meaningful activity and their observations of the negative effects on people living with dementia who lack this purpose. Non-positive *Dementia Unseen* positions are created through the same mechanism as discussions regarding activity are framed in the context of dementia. The emotional attachment of the group is a barrier to positive positioning more frequently than facilitative. Whilst *Supported* has the greatest percentile occurrence of positive positions with 14 out of 15 allocated positions meeting the requirements for positive positioning, *Dementia Unseen* positions are more frequently allocated, with 26 occurrences and only 1 positive allocation. FB and to a lesser extent, FA and FC contribute positive *Belonging* positions (9 positive positions from 16 overall) but, similar to LPD, *Able* positions are less positively observed (7 positive positions form 23 overall). Positive Able positions are applicable to the *Capable* rather than *Superior* to sub-theme.

The emotional attachment of the participants is visually presented as a facilitator and barrier to positive positioning of each thematic position in Figure 52.

Figure 52: Balancing Framework: Emotional attachment



The emotional attachment shared by the participants informed a barrier (visually presented as solid line) to achieving positive positioning in the *Able* and *Dementia Unseen* themes.

Although barriers to positive *Belonging* positions were observed, these were not evident in all participants with emotional attachment. This less substantial barrier is indicated in a dashed line to indicate the fragility of this restriction to positive positioning. The route to positive *Supported* positioning is visually unhindered as emotional attachment facilitated this positioning value within the theme.

8.1.2 Practical experience

The healthcare worker group is formed by their practical experience of working with people living with dementia. This practical experience is used to inform relatively unchanged non-positive *Able* positions during both case studies. *Belonging* positions are also consistently non-positive with only HWD allocating a higher percentage of positive positions to this theme during Sally's case study. Negative *Belonging* positions are aligned to the *No* blame sub-theme as people living with dementia in the care home are regarded as purposefully behaving in an unhelpful manner and this attribute is transferred to other people living with dementia during case study discourse. The positioning by the group is contradictory, although persistently negative, as people living with dementia are positioned as incapable and therefore lacking capacity but equally to blame for actions, which healthcare workers regard as wrong.

Able positions dominate the discourse of this practically experienced group, having the highest occurrence of any theme in both case studies (36 and 54). Delivery of the AI outcome does not affect the discourse concerning this theme with a consistent number of positive positions between the case studies (22% to 24%). *Dementia Unseen* has the second highest number of overall positions during Sally's case study (28), which is a substantial increase compared to this theme's positions during Beryl's case study (6). The AI outcome is observed to have an effect on the discourse of the group as they discuss positions within this theme following its Delivery. Practical experience does not automatically inform negative positioning of this theme or act as an enabler for positive positioning, although a small increase of this latter positioning value is observed between case studies (17% to 29%). *Belonging* is allocated the least number of positive positions between the themes in Sally's case study (19%) although only 26 overall positions are allocated compared to the dominant *Able* theme (56).

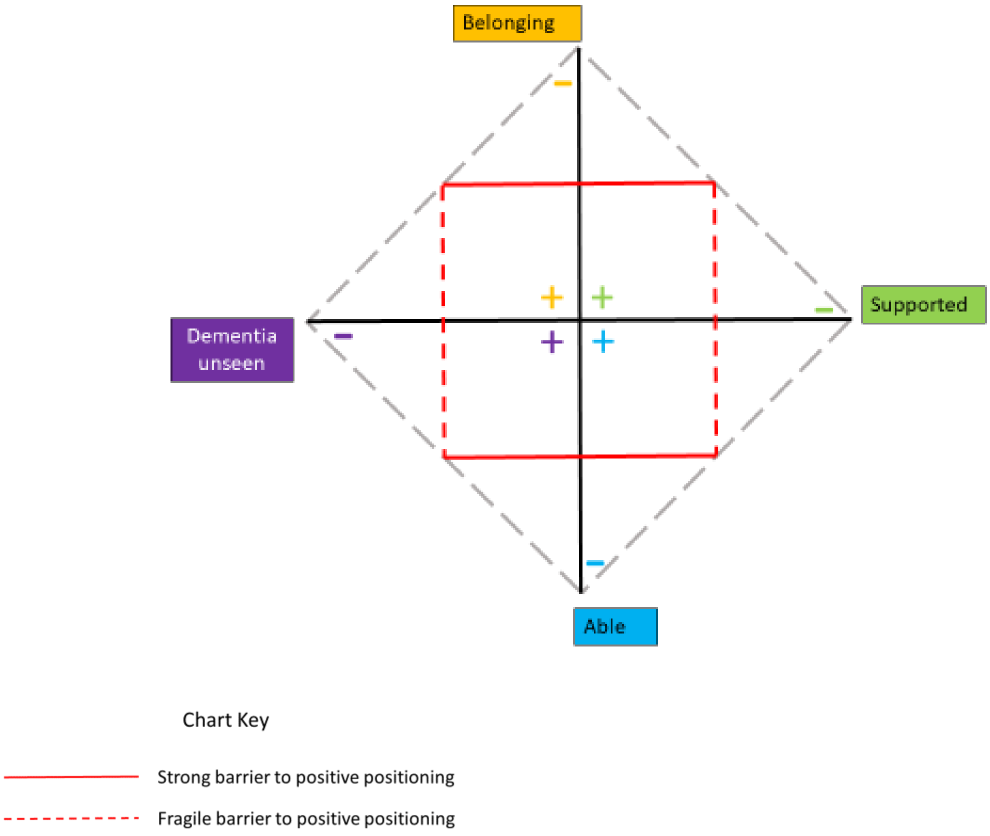
Supported positions have the highest positive occurrence (35%) of all themes in the Sally case study although individual group members widely differ in this allocation (0% to 80%).

LPA, with previous employment as a home carer, represents the most practically experienced layperson group member. LPA's positioning is consistent with the healthcare worker group with allocations of non-positive positions observed in *Able* (43%) and *Belonging* (40%) following Delivery whilst remaining themes have higher positive allocations. Consistent with other lay people, LPA's overall discourse has a higher allocation of positive positions compared to the healthcare worker group, despite their thematic alignment.

Family members/carers refer to practical experiences although their allocation of positions is more typically informed by emotional attachments. Following the emotionally driven positioning of *Dementia Unseen*, the *Able* theme has the second lowest occurrence of positive positions following Delivery. Although this positioning is also informed by the emotional attachment, it is also consistent with other practically experienced members of the healthcare worker and lay people groups.

The practical experience of the participants is visually presented as a facilitator and barrier to positive positioning of each thematic position in Figure 53.

Figure 53: Balancing Framework: Practical experience



The practical experience shared by the participants informed a barrier (visually presented as solid line) to achieving positive positioning in the *Able* and *Belonging* themes. Although barriers to positive *Dementia Unseen* and *Supported* positions were observed, these were not evident in all participants with practical experience. This less substantial barrier is indicated in a dashed line to indicate the fragility of this restriction to positive positioning.

8.1.3 Positioning Identities

Five conceptual identities were reported as part of the findings:

- Threatened positioner
- Stagnant positioner
- Open positioner
- Empowered positioner
- Reluctant positioner

The positioning identities are ephemeral, similar to allocated positions, although participants were observed to favour particular identities following Delivery. The dominant identity for participants observably influenced the allocated positions in the individual Balancing Frameworks.

Prior to Delivery, threatened positioners are empowered by their practical or emotional attachment. LPD had the highest number (11) of allocated positions prior to Delivery as other participants were led by her experience with her father. Similarly HWE has the longest experience in dementia care (6 years) of the group members and holds a senior position and is therefore traditionally empowered. The threatened position is derived from the participant's reluctance to relinquish this influence following Delivery. Whilst LPD attempted 2nd order positions to negatively position people living with dementia more frequently following Delivery (1 to 5), her Balancing Framework illustrated a greater number of positive positions for Sally overall, indicative of the ephemeral existence of the identities. HWE, however, observed minimal movement from the threatened identity, informing increased allocations of negative positions in three positioning themes. The remaining theme, *Dementia Unseen*, observed a small increase in positive positioning from a zero baseline (17%). The threatened positioner identity informs a barrier (observed as a solid line in the framework) to positive positioning within all four themes, although if participants expose themselves to other positioning identities during discourse these barriers may be overcome.

Stagnant positioners are observed to have emotional and/or practical experience. No dominant stagnant positioners were observed in the lay people group. Whilst health care worker participants with this dominant identity observed minimal changes in their positioning between case studies, both family members/carers participants observed positive change in the *Supported* theme (FA: 20% to 100%, FD: 0% to 100%). The positive change is consistent with other family member/carer participants, indicating that Delivery combined with the emotional attachment of this group facilitates positive positioning within this theme whilst other dominant stagnant positioners may still be presented with a barrier.

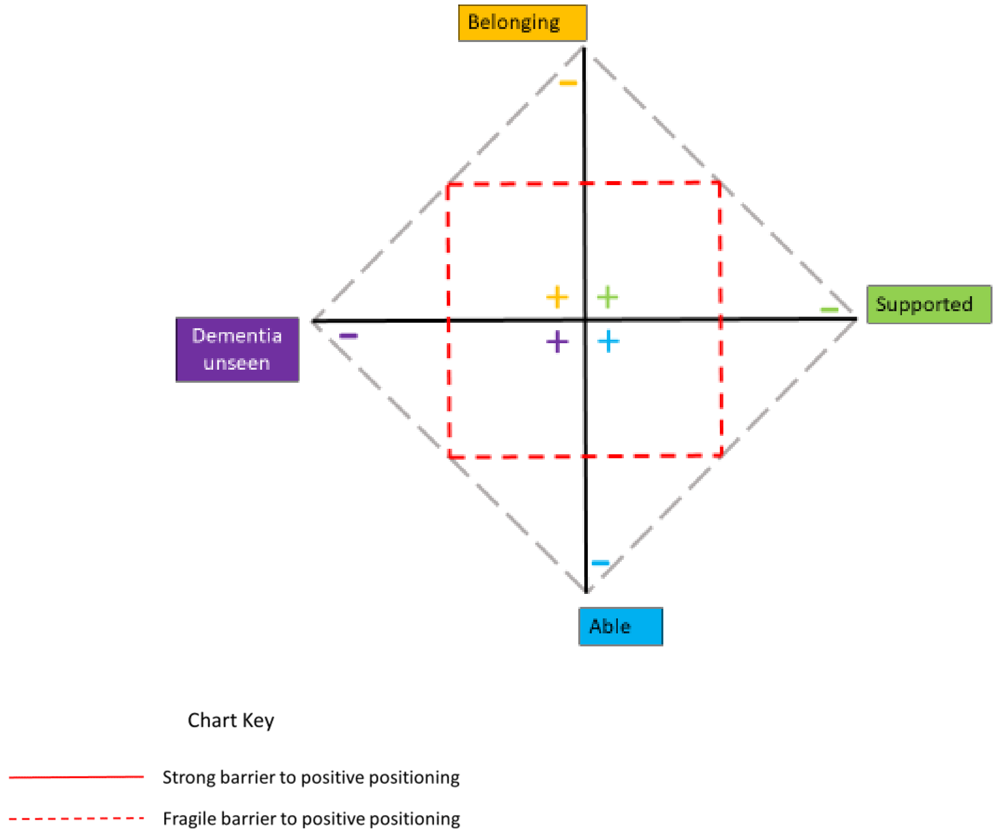
Open positioners were observed in all three societal groups but were more commonly found in the lay people group, with three members holding this dominant identity. The open identity facilitates positive positioning as the participants are inclined to accept new perspectives, enhancing the effect of Delivery. The pre-eminence of the lay people group in this identity is informed by the lack of emotional or practical experience in the group. Whilst other groups may be influenced by the Delivery, they already hold practical and emotional influencers for positioning. The lay people, without this prior experience, have a greater inclination to accept the AI outcomes for the perspectives of the people living with dementia in the film.

The effect on the Balancing Frameworks of empowered positioners following Delivery are similar to those with dominant open identities. Empowerment through AI facilitates access to positive positioning within the four themes. Empowered positioners also attempt to influence the discourse of other group members with observable increases in positive 2nd order positions in those participants with this dominant identity (HWC: 2 to 8, HWD: 0 to 6, LPE: 1 to 7, FC: 2 to 4).

Reluctant positioners are influenced by the positions offered by others. HWG has the least practical experience of the healthcare worker group and is influenced by the senior and more experienced, HWE. HWG's discourse is therefore presented with the same barriers as HWE's threatened positioner. LPF follows the experience of LPD during Beryl's case study but is influenced by the empowered LPE following Delivery, giving LPF the same access to positive positioning as the empowered identity. The reluctant positioner identity indicates participants who are disinclined to offer independent positions but may be subject to divergent barriers or facilitators to positive positioning depending on their influencers.

The impact of the variance of positioning identities on the Balancing Framework is illustrated in Figure 54.

Figure 54: Balancing Framework: Positioning identities



Whilst certain positioning identities create barriers to positive positions (Threatened, Stagnant) and others may facilitate desirable positions (Open, Empowered) the ephemeral behaviour of positioners is represented by the presence of insubstantial barriers to the positive core of the Balancing Framework. A dominant positioning identity does not prevent access to other identities, allowing positive positioning to occur in all participants.

The Balancing Framework: The positioner

Synthesising the analysis of the three influencers and their respective Balancing Frameworks informs the presentation of a final Balancing Framework, which illustrates the accessibility of positive positioning of people living with dementia. This framework is presented in Figure 55.

This figure synthesises the findings in Figures 52, 53 and 54 to illustrate the three conceptual themes (practical experience, emotional attachment and positioning identities) together in the Balancing Framework. The red line displaying the barrier to positive positioning (as previously illustrated in the earlier figures) now represents the three themes, with the meaning of the red dashed line continuing to denote a fragile barrier. The blue curved triangles within the triad illustrate that the three themes rotate within the Balancing Framework and act as potential facilitators or barriers for all four conceptual positioning themes (Belonging, Able, Supported, Dementia Unseen). The key for this Balancing Framework is observed again in Figure 55.

Figure 55: Balancing Framework: The positioner

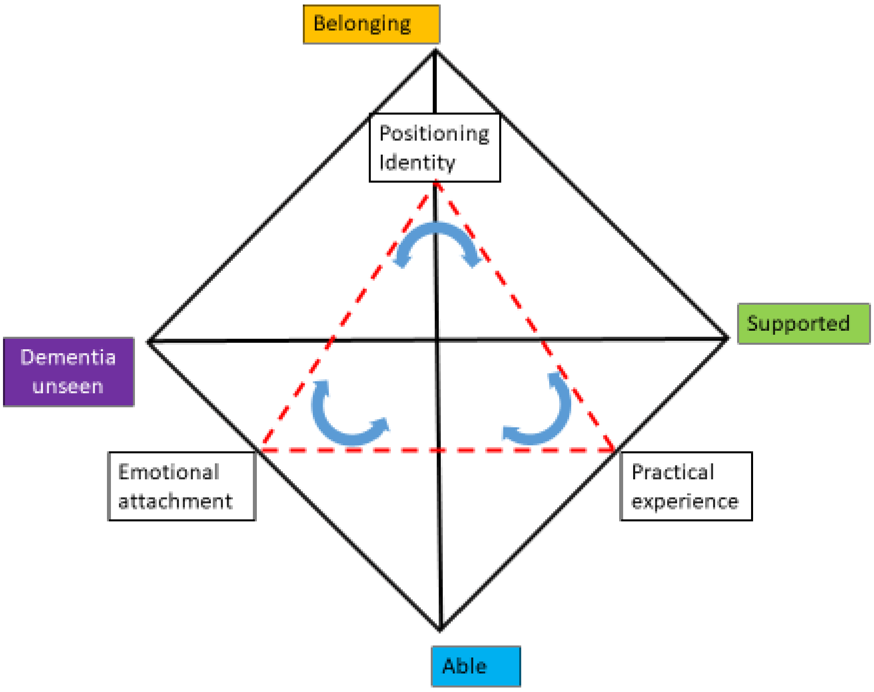
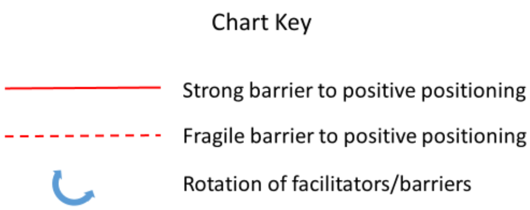


Chart Key



The three influencers are presented as potential barriers to positive positioning dependent on their content but equally may act as facilitators, hence the application of the less substantial dashed line to indicate their presence. The arrows within the framework indicate that the influencers are not statically observed within specific themes as the triad is constantly revolving within the framework, influencing positions within all themes.

By understanding the triadic influencers on individual positioners, the susceptibility of the individual to the influence of Delivery on the positioning of people living with dementia is visually realised.

8.2 People living with dementia's experience of the Balancing Framework

The allocation of positions within the Balancing Framework indicates the final stage of analysis of a singular piece of discourse. Positions allocated to the centre of the framework have been assessed as meeting the requirements of positive positioning as defined by the four people living with dementia who engaged with the AI process. To fully synthesise the positioning findings from the case study discourses it is therefore crucial to revisit the

Discovery and Dream phases to ascertain how these positions may be perceived by the person living with dementia being positioned.

The analysis of contributory factors observed during Discovery informed the development of the Balancing Framework. These factors defined positive positions, which are allocated by others and represented external requirements for positive positioning. The experience of receiving a position was divulged through the identification of internal requirements, necessary for a person living with dementia to experience a positive outcome, respective of the external position. The factors identified as internal requirements produced three conceptual themes:

- Emotional need
- Abilities used
- Empowered

The analysis of the ideal world identified during Dream identified the theme of *Ourselves*, indicating the need for people living with dementia to achieve the positive internal requirements identified in Discovery, for positive positioning to be experienced. Whilst the positioning by others cannot be analysed through the internal requirements of people living with dementia, these requirements are acknowledged as crucial to the lived experience of being positioned. The internal requirements are presented here in their relation to the Balancing Framework outcomes before the presentation of a visual synthesis of the internal requirements location within the Balancing Framework.

8.2.1 Emotional need

This internal requirement focusses on the relationship between the positioner and person living with dementia and their location whilst positions are allocated. The requirement is conceptually similar to the influence of emotional attachment on positioners. A relationship with a family member/carer, which is regarded as supportive by the person living with dementia enhances the emotional requirement for positive positioning. Similarly, a relationship with a positioner, which is regarded by the person living with dementia to be unsupportive or abusive is unlikely to meet this requirement.

All four people living with dementia shared Discovery narratives, which took place in non-objectionable locations from their perspective. The positivity of the location enhanced the opportunities for the person living with dementia to feel positively positioned. During the Beryl case study the group suggested that Beryl may be reluctant to attend a day centre but HWE suggested that this could be overcome through misinformation:

HWE:

> *Like, some people do think they've come to like a hotel so that might be something, that kind of impression that's been put on Beryl to go if she doesn't want to go, erm, yeah. Yeah, have dinner.*

Beryl's reluctance to attend could initiate a perception of the day centre as a negative location reducing her ability to accept positive positioning by others whilst attending. Beryl's internal emotional need is not achieved, informing a barrier to recognising the positive positions allocated by others to her. Pauline's recommendations during Design are informed by negative experiences during hospital visits:

> *Any professionals, health, to treat you like, with respect and dignity. Like they would anybody.* (Pauline)

Pauline identifies healthcare professionals as members of society who she demands positional change. Her previous experience, similar to Beryl's fictional case study, may negatively impact on her internal emotional need when positioned in these locations, creating a barrier, which reduces her ability to experience positive positioning, even if the isolated position would be centrally positioned within the Balancing Framework.

8.2.2 Abilities used

This internal requirement is informed by the person living with dementia's perception of their own practical abilities. It is closely tied to the practical experience influencer of positioners whose observations through experience inform their own beliefs regarding the abilities of people living with dementia. Pauline addressed the positioning of others regarding the ability of people living with dementia during Design:

> *A lot of people go on about all the things you can't do now and not what you still do.* (Pauline)

However, the allocation of positive practical abilities to a person living with dementia who does not share this belief may not create an experience of being positively positioned. Sue's narrative did not meet the internal requirements of this theme as it concerned a pre-diagnosis ability and therefore created a barrier for her to experience post-diagnosis positive positioning. Whilst the other three people living with dementia recognised that the practical ability discussed in their Discovery narrative was not exclusive to them, their use of the ability allowed them to experience desirable positions. Sue's negative perception, that her ability was unremarkable denied the positive position implied by her manager's actions. The manager at the bakery had positioned Sue as the person with the greatest practical ability but Sue's own internal rejection of her ability, does not allow her to experience the position as overwhelmingly positive.

When discussing Sally's driving ability, LPE positively positions the person living with dementia:

LPE:

Yeah. So, she certainly hasn't deteriorated.

Whilst, FA allocates a negative position:

FA:

And driving is dangerous.

Entered into the Balancing Framework, LPE's position would be allocated in the centre to denote its positive alignment. FA's statement would be located at the exterior tip of the theme as it does not meet the requirements for positive positioning. However, if Sue's perception of her abilities during her own narrative is transferred to the fictional, Sally, neither position results in the person living with dementia experiencing a positive position. If Sally has a positive view of this internal requirement, LPE's positive statement can be accepted although having this positive disposition does not prevent the experience of negative positioning by FA.

Having a negative disposition within this internal factor may also facilitate the power of negative positions for as positive positions cannot be experienced, negative discourse is more readily accepted.

8.2.3 Empowered

This internal requirement is dependent on the person living with dementia's perception of their personal value to others and the value of their opinions, thoughts and ideals. Feelings of empowerment may be derived from the reactions of others during interactions but are initially located within the person living with dementia's belief that they have this value. People living with dementia who negatively judge their value are less likely to recognise when others attempt to positively position them in this way. Although, Design was a mechanism to inform other members of society to meet the external requirements for positive positioning,

The absence of this internal requirement is also observed in Sue's Discovery narrative as she regards herself as unimportant and easily replaced, nor does she regard her opinions as having worth to others. This negative perception of self drove the development of the Dream theme, *Ourselves*, and the ideal that people living with dementia 'are no longer our own worst judges'. Although a person living with dementia may be positively positioned as having value, they will not experience this position unless they share this belief.

LPF positions Sally as having value beyond her individualism, by recognising that she is still an active part of society:

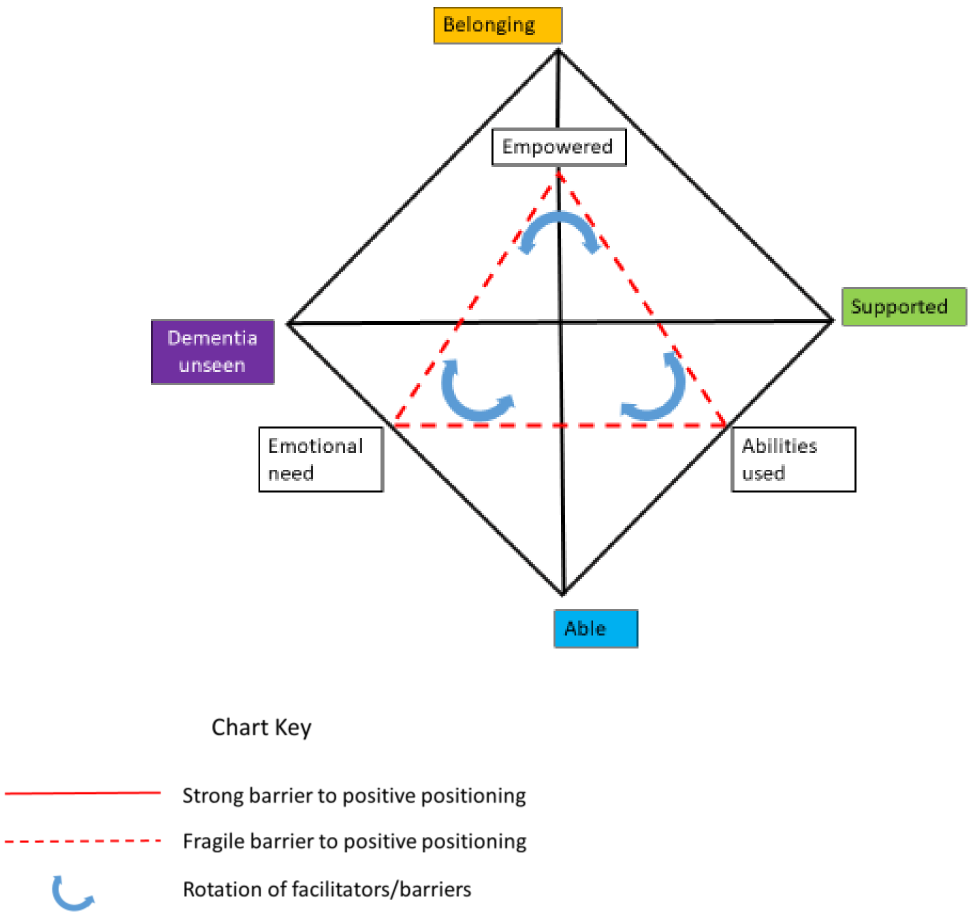
> *LPF:*
> *So, obviously they're still part of the community, aren't they?*

The position is centrally located in the Balancing Framework as Sally is regarded as having value and input into the experience of the wider populace. However, if Sally did not perceive her value as worthwhile, this positive positioning would be prevented from reaching the centre of her internal Balancing Framework, therefore denying the experience of being positively positioned.

8.2.4 The Balancing Framework: The internal experience

Synthesising the analysis of the three internal requirements and their relationship with the Balancing Framework informs the presentation of a final Balancing Framework, which illustrates how these requirements may prevent or facilitate the experience of being positively positioned. This framework is presented in Figure 56.

Figure 56: Balancing Framework: The internal experience



The three internal requirements are presented as potential barriers to experiencing positive positioning. The less substantial dashed line is used to indicate their presence as the barriers are ephemeral depending on the context of discourse. The arrows within the framework indicate that the internal requirements are not statically present within specific themes as the triad is constantly revolving within the framework, influencing the experience of positions within all themes.

By understanding the triadic internal requirements of individual people living with dementia, barriers for individuals to experience positive positioning may be more readily identified.

8.3 Narrative statement framework

Through the analysis of the Discovery and Dream phases of AI, conceptual themes and sub-themes were developed to identify the context of positive positioning envisioned by the participants. The process of Design empowered the people living with dementia to share their narratives and desires with other societal groups who, through Delivery, offered case study based discourse, which was directly influenced by the AI.

The conceptual sub-themes identified during Discovery and Dream were illustrated as variably positively positioned by societal group members following Delivery. By synthesising the analysis of these sub-themes, the positioning analysis of the case studies alongside the positioning influencers, two observable ingresses are detected. These ingresses illustrate the positional journey of a narrative statement to achieve positive positioning. The narrative statement framework illustrating this journey is presented in Figure 57.

Figure 57: Narrative statement framework

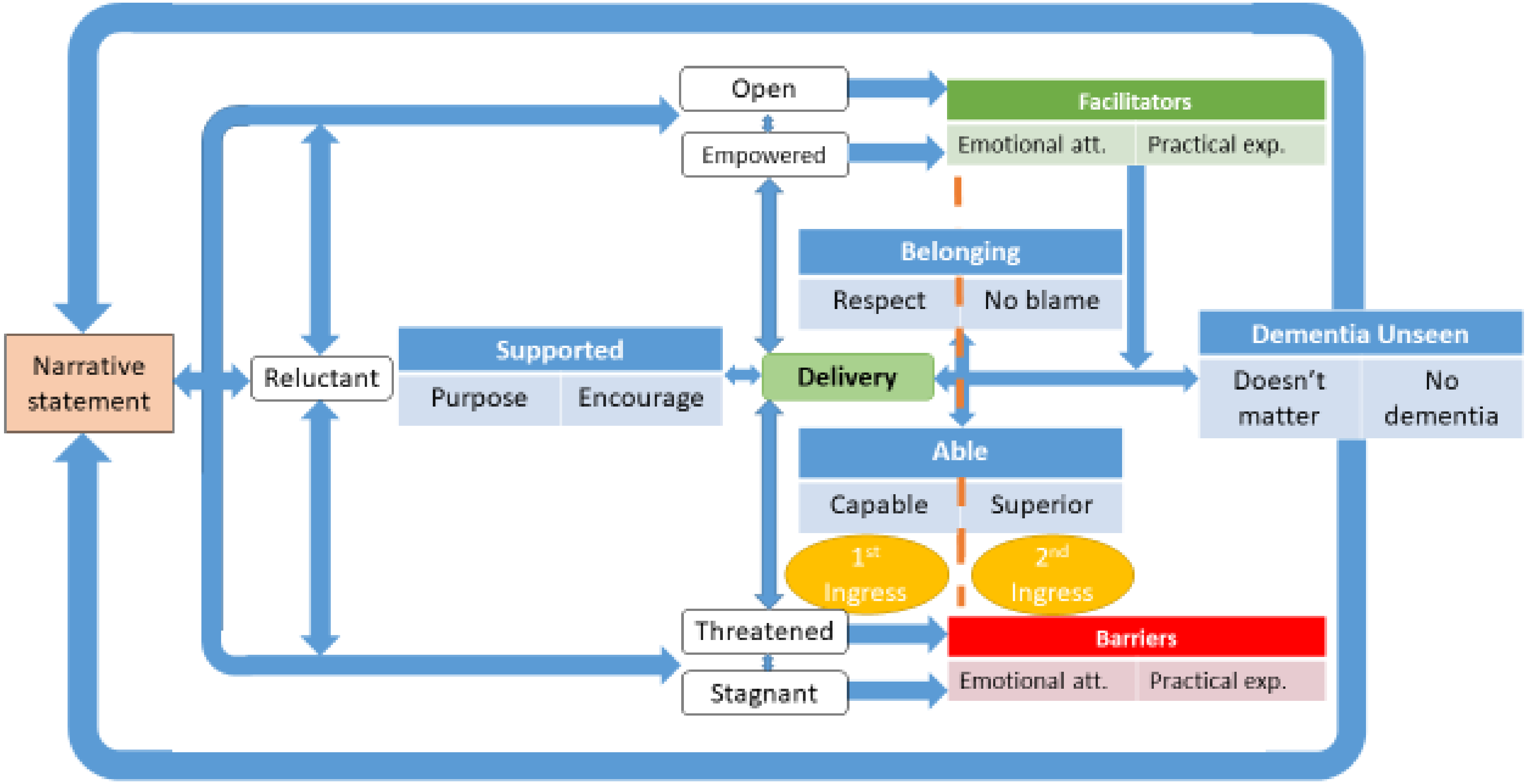


Chart Key

The narrative statement is observed at the beginning of the discourse journey. Each singular piece of discourse has the potential to allocate a positive position relating to one of the identified themes. Whilst each single piece of discourse may contribute a position, it exists within a larger storyline (van Langenhove and Harré, 1993), which is also subject to the pre-existing influences of experience and relationships between people within the discourse. The statement is informed by the ephemeral positioning identity, which acts as a facilitators or barriers to positive positioning. This is illustrated in the framework by the directional arrows to and from each positioning identity, with some identities providing further direction to positive positioning and others having no access.

Reluctant positioners will typically follow other positioning identities and this is illustrated by the directional arrows to the four other identities. All positioning identities have access to Delivery. For Open and Empowered positioners this is one route to positive positioning whilst their identity also provides access to use or overcome practical and emotional attachments to allocate positive positions. Threatened and Stagnant positioners may access positive positioning through Delivery but otherwise will be prevented from offering positive positions, through closed discourse concerning their own emotional and practical experiences.

The first ingress identifies the conceptual sub-themes, which are more readily accessible to positive positioning and are therefore less likely to have this positioning impaired by barriers caused by non-adaptive positioning identities. The second ingress identifies the conceptual sub-themes, whose positive positioning is generally more restricted by non-adaptive positioning identities but may still be accessed through AI.

Directional arrows are presented as moving in both directions to indicate the erratic and ever changing evolution of discourse. However, as the framework illustrates only one narrative statement, a statement which enters the barriers area has no further development. The arrows indicate a consistent return to a new narrative statement, which will also undertake the journey within the framework. Statements, which end in the barriers section are not indicated to return to the narrative statement as positive positioning has not been achieved. This does indicate that a new narrative statement will not be made but highlights the frameworks commitment to the positive journey, to consistently align with the AI methodology, which was used to inform its development. The justification for allocating sub-themes the first and second ingresses will now be presented, synthesising the outcomes of all four phases of AI.

The 1st Ingress

Supported: Purpose

The sub-theme is allocated positive positions more commonly than any others. Recognising that people living with dementia requires meaningful purpose does not require anything from the positioner beyond the stated purpose. The perlocutionary force of a positive *Purpose* sub-theme may instigate the pursuit of purpose in others but does not instigate an action in the positioner themselves. It is therefore relatively benign for a positioner to allocate a positive position within this sub-theme.

Prior to Delivery, participants are observed as open to entering the first ingress, with few denying the requirement of activity. However, negative positions are observed when activities, which lack purpose are considered such as the virtual shopping experience for Beryl:

> *HWB:*
> *Yeah, 'cause they can do things like shops in them, can't they? When you go shopping.*

Through Delivery, the four people living with dementia educate the societal groups regarding their own concepts of purpose, with Gavin discussing vocational purpose through his employment and Pauline describing pleasurable purpose, through her canoeing experience. Sharing these experiences provides entry to the first sub-theme within the ingress, which allows for positive positioning without perlocutionary commitment from the positioner.

Supported: Encourage

The positive achievement of this sub-theme suggests that the positioner has already entered the first ingress, as its achievement is dependent on the belief in positive *Purpose*. There is a greater commitment from the positioner as a positive *Encourage* position is an active position and may include defined recommendations for people living with dementia. Both case studies inquired about the people living with dementia attending a day centre. Pre-Delivery, it was universally agreed that Beryl should attend a day centre but following Delivery, participant's discourse was regularly observed to move positively within the ingress. The dominant open positioner, LPE encouraged Sally to consider prior interests (bowling) and continue with current activities, rather than attend a day centre:

> *LPE*
> *She can carry on as normal, I would say…No, I don't think she'd benefit from a day centre, attending a day centre, 'cause she already goes…*

The open positioner identity allows LPE to access the ingress with language, which reflects Pauline's Encourage discourse during Delivery, regarding the canoe trip:

> *I was asked would I like to do it…it made me feel normal.* (Pauline)

The repeated concept of 'normal' illustrates that accessing this part of the ingress, does not require any creativity from the positioner but only an acceptance and encouragement of the person living with dementia's purpose.

HWG's suggestion that Sally should use virtual reality to simulate a driving experience following Delivery, is indicative of her reluctant positioner identity, influenced by the threatened HWE who uses the discourse to offer further negative positions, albeit in more commonly negatively allocated 2nd ingress sub-themes. Although AI has offered a route into the positive ingress for the positioners, their positioning identities have denied them access during this particular discourse.

Supported is illustrated to have the most readily accessible sub-themes within the first ingress. Following Delivery, both the healthcare worker group (17%) and family member/carer group (86%) witness the greatest growth in positive positioning within the theme. Whilst the 55% positive growth in lay people positioning is only the third highest within the four conceptual themes for this group, this is indicative of the higher prevalence of positive positions within this theme pre-Delivery compared to the themes, which observed greater growth.

Able: Capable

Although this sub-theme is positively achieved through the endorsement of ability it is located further along the first ingress as, similar to *Encourage,* there is a potential physical perlocutionary outcome. The sub-theme may be regarded as less benign by the positioner than *Encourage,* as the *Capable* status has the potential to promote greater independence for the person living with dementia.

LPD actively promotes the independence of Sally and her husband, following Delivery, due to her belief in their capabilities:

> *LPC:*
> *Well, they obviously don't need any help, do they, in the house to look after themselves or whatever? But they, yeah, I think they do need.. (*Able +)

Being assured that other people believe in the person living with dementia's capabilities reflects Pauline's relationship with her friend, shared during Design and Delivery:

> *I was really proud that she'd put that trust in me…she trusted that I'd know what I was doing.* (Pauline)

Positive *Capable* positions dominated the allocation of positive discourse within the *Able* theme, informing its placement within the first ingress. Positive *Able* positioning witnessed the lowest growth in the four themes in both healthcare worker (2%) and family member/carer groups (23%). This outcome has previously been discussed in relation to this theme and the practical and emotional attachments of these two groups. The lack of growth is also indicative of the lack of positive *Superior* positioning, which is located in the second ingress. Positive *Able* positioning is achieved through the *Capable* theme, thus the overall lack of positive growth within the theme does not indicate the requirement to place *Capable* within the second ingress but rather supports the placement of *Superior* within this more difficulty accessed ingress.

Belonging: Respect

Prior to Delivery, the minimal amount of positive positioning within the *Belonging* theme for all groups was dominated by the *Respect* sub-theme. However, pre-Delivery *Respect* positioning was generally neutral, with participants tending to discuss people living with dementia as one homogenous group without explicitly denying the requirement of respect. The decision for Beryl to attend a day centre was often led by a narrative that this is what all people living with dementia should do, rather than considering her needs individually.

Delivery opened greater access to the ingress through the narratives of people living with dementia. Colin shared the experience of his wife demanding respect for him and other service people on a march:

> *She said 'show respect' and (wife's name) made sure that everybody clapped all the way to the end…that's how it should be.* (Colin)

Discourse developed following Delivery with participants offering more individual positions for people living with dementia. LPB created a positive *Respect* position when the relationship between Colin and his wife was reflected in her positioning of Sally and her husband:

> *LPB:*
> *It's all..it said..what d'you think would help Sally? Well, surely it's her husband and Sally?*

LPB was empowered by AI to directly oppose the case study questions, which had been accepted unquestioningly prior to Delivery. LPB's discourse denied the validity of the question, as it did not respect Sally's spousal relationship.

The positive allocations of *Respect* positions is countered by the more negative accounts of *No blame* positions within the *Belonging* theme, which is situated in the second ingress.

However, the increased prevalence of positive *Respect* positions is indicated in the theme having the second highest growth in positive positioning overall in both healthcare worker (15%) and family member/carer (43%) groups and the highest growth in the lay people group (69%).

The 2nd Ingress

Belonging: No blame

Negative *No blame* positions were observed as conflicted as the person living with dementia was not blamed for their diagnosis but could be blamed for their actions following diagnosis if the positioner did not approve of them. The negative position provides an illocutionary safety net for the positioner, as the person living with dementia is allocated blame whilst the positioner is absolved. The dominant negative discourse within *Belonging*, was observed in this sub-theme, informing its placement in the second ingress.

Sue described the language used to blame her for actions, which others opposed:

> *There's got to be another word that people can use that doesn't take people down with the word 'stupid'. There's got to be. Because that is so upsetting. It's an abusive word.* (Sue)

Following Delivery, FD negatively positioned Sally and her husband, using similar direct language:

> *FD:*
> *That's double trouble.*

FD's suggestion that the couple will be 'trouble' indicates her dominant stagnant identity. Prior to Delivery, FD had offered positions to suggest that people living with dementia were 'trouble':

> *FD:*
> *Because they'll turn on you and...*

The stagnant identity prevents entry into the second ingress, even following Delivery, whilst positioners with other identities suggested that the spousal relationship was a potential source of support and strength. Sally and her husband were subject to divergent positions, with her husband regularly regarded negatively within the *No blame* sub-theme as Sally was more positively assessed following Delivery.

The ongoing occurrence of negative *No blame* positions following Delivery indicates its placement in the second ingress and the difficulty some positioners may have in dismissing actions as blame-worthy.

Able: Superior

The placement of the *Superior* sub-theme within the second ingress is well informed by the lack of positive positions observed in this context. Delivery was observed to have a small effect, although this was the greater establishment of neutral rather than negative positions. The limited amount of positive data in the sub-theme does not correspond to its importance in the narratives shared by people living with dementia during Design with *Superior* positions only absent in Sue's discourse. This supports its position within the 2nd ingress, as the position was important to the people living with dementia during the AI workshop but rarely positively achieved by participants in the three discussion groups.

Gavin illustrated the *Superior* sub-theme in his own narrative when discussing his colleague's requests for assistance with the new ticketing system:

> *They come to you for advice, so that's much better.* (Gavin)

Positive *Superior* positioning was attempted for Sally but often to the detriment of her husband. Positive positioning was therefore not achieved as Sally was only regarded as superior to another person living with dementia, whilst Gavin's, and the other two narratives from people living with dementia, positioned the person living with dementia as superior to people without dementia. LPB offered a position, which expressed Sally's superior abilities:

> *LPB:*
> *Sally seems to be doing everything?*

The secondary positioning of her husband, however, resulted in the discourse only achieving a neutral allocation. The example does, however, illustrate that AI prompted discourse to attempt this positive positioning although the difficulty in achieving this, justifies its position within the second ingress.

Dementia Unseen: Doesn't matter and No dementia

The final sub-themes are presented together as an indication of the negligible differences between occurrences of positive positioning within *Doesn't matter* and *No dementia* based discourse. The difficult of entering the second ingress and accessing positive positions within this theme is illustrated in the positioning by family member/carers, were there is a decline in positive positioning (-2%) following Delivery. This is the only theme in any societal group where a decline in positive positioning is observed following Delivery. Countering this decline, is a 57% growth in positive positioning in the lay people group following Delivery within the theme. This growth is consistent with this societal group's positive growth in positions in all themes and is indicative of their relatively low emotional and practical experience and higher prevalence of open and empowered positioners.

Negative positioning does still occur within the lay people group, with LPB continuing to suggest that dementia is the informant for allocating positions after Delivery:

> *LPB:*
> *We don't know who's the worst.*

The ephemeral nature of positioning identities is illustrated as the stagnancy in LPB's positioning here is inconsistent with her dominant open positioner identity and her acceptance of the Delivery narratives. However, this movement towards the stagnant identity is also observed in this second ingress theme, illustrating the barriers to positive positioning at this point of the ingress.

Colin informed the *No dementia* theme by describing the lack of judgement from others, he experienced when people did not know he had Alzheimer's disease:

> *Sometimes if I'm in chapel and talking, right, people don't even know I've got Alzheimer's right, and the people don't judge.* (Colin)

The empowered HWC, illustrated similar positioning when discussing Sally's decision to reduce her driving distances. HWC did not indicate dementia as a cause for the change in Sally's behaviour but described the alteration as typical of 'anyone':

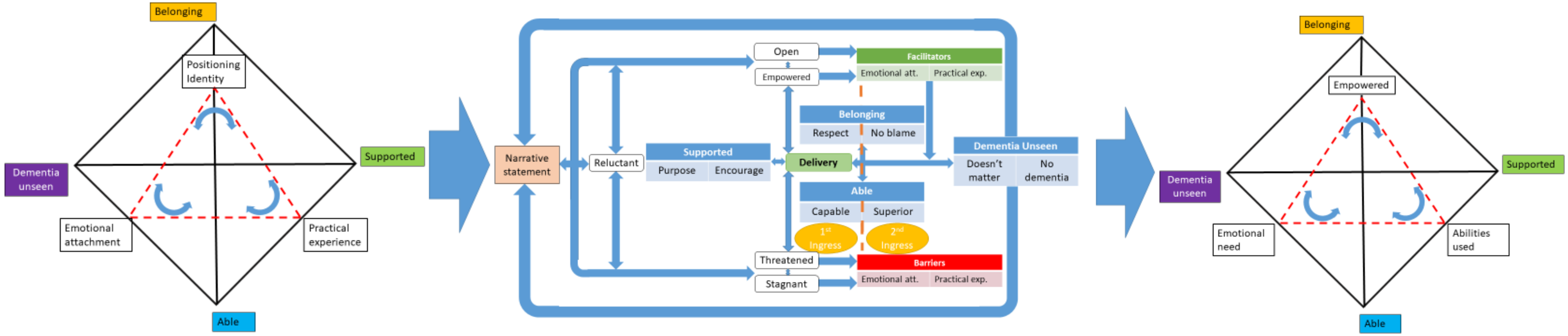
> *HWC:*
> *It's like anyone though, isn't it? If you, if something happens like that you don't want to do it, do you again? So..*

Dementia Unseen is a key heuristic for the subsequent allocation of positive positions in the other positioning themes. Its location at the end of the 2nd ingress (see Figure 57) is testament to the power of dementia to influence the positioning of people living with dementia by other members of society. All three societal groups observed a higher occurrence of negative *Dementia Unseen* positions compared to the percentile occurrence of negative positioning in the additional three themes. Positioning the person living with dementia, without using dementia to directly inform the position is evidently more challenging for the participants in all three groups than when they attempt positioning within the other three themes. Fulfilling the requirements of positive positioning within this theme increases the likelihood of positive positioning in other positioning themes. A position that positively achieves the *Doesn't matter* sub-theme will consequently allow other thematic positioning to occur without the person's dementia ‘matter’ing. A positive *No dementia* position can have a greater effect, as the person is regarded during the act of positioning rather than their dementia.

8.4 The interconnected process

The three frameworks presented in this chapter do not exist in isolation. As independent frameworks they provide only part of an understanding of the allocation and experience of positive positions for people living with dementia. Discourse begins with the positioner whose locutionary act triggers the allocation of a position. What is meant by this discourse, or the illocutionary act, is dependent on the influencing factors detailed in the narrative statement framework. The final position experienced by the person living with dementia is guided by a further triad of influencers, individual to each person. It is only once discourse has travelled through all three frameworks, that the person living with dementia may experience positive positioning themselves. The interconnected process is illustrated in Figure 58.

Figure 58: The interconnected process



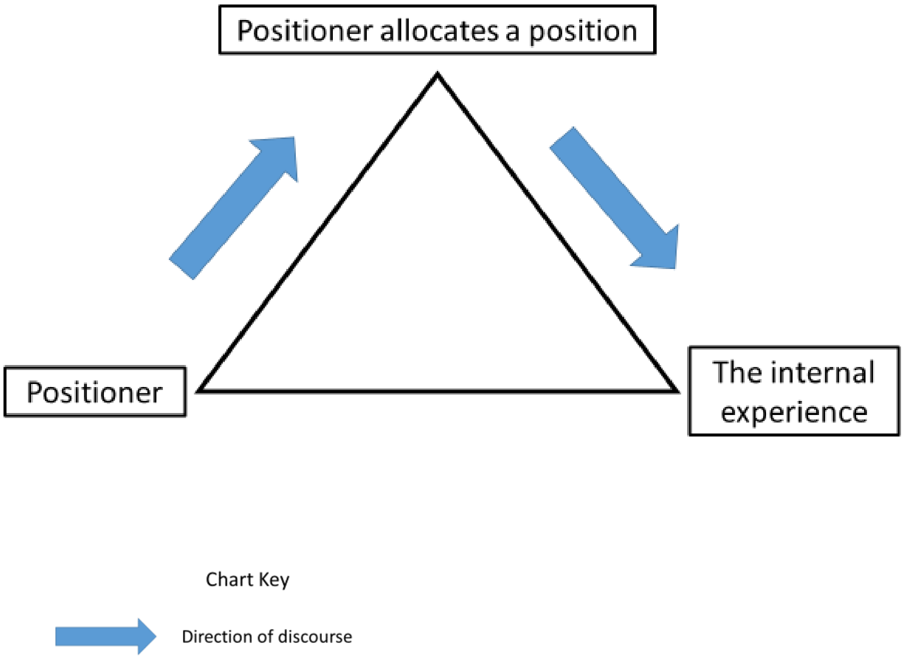
The Balancing Framework: **The positioner** (Figure 55), represents the first part of the interconnected process as the strength of the positioner's influencers are illustrated in the internal triad. In the positioner's personal triad, a dominant positioning identity may be identified. Although the outcomes of AI informed the development of this triad, any positioner can be allocated this personal framework without access to Delivery, as observed in the positioning analysis of Beryl's case study.

This personal triad is connected to the Narrative statement framework (Figure 57) as the **positioner allocates a position**. It is here, that Delivery may be accessed to influence the position allocated to people living with dementia. As illustrated previously, this is an ongoing process with each narrative statement processed through the framework. In the interconnected process, the identified position and its value is transferred to the Balancing Framework: The internal experience (Figure 56).

The Balancing Framework: **The internal experience** illustrates the person living with dementia's perception of the allocated position. As illustrated, this model considers the internal requirements for the person living with dementia to accept the positions allocated by others to them. Whilst the location of the allocated position may differ between the Balancing Frameworks of the positioner and the person living with dementia, it is the latter framework, which enables the person living with dementia to assess whether AI has influenced positive positioning.

The interconnected process between the actors and action is streamlined as three linear points within the discourse journey triad in Figure 59..

Figure 59: The discourse journey triad



This triad simplifies the interconnected process into three actions. First, a positioner independently exists with their own internal triad. Second, the positioner undertakes a locutionary act, which allocates a position. Finally, the person hears the discourse and personally receives this as a positive, neutral or negative position depending on their own internal experience.

8.5 Summary

The experience of positive positioning for people living with dementia is deeply personal. It relies not only on the experiences and beliefs of the positioner and their discourse but also their own internal experiences and beliefs about themselves. Through the production of an AI film, people living with dementia are able to influence the discourse of other members of society, as well as recognise some of the internal factors which influence how they position themselves.

AI can be used by divergent societal groups in differing phases of the 4D (Discovery, Dream, Design, Delivery) cycle to instigate positive actions between participants. Both people living with dementia and positioners are influenced by internal triads (namely, practical experience, emotional attachment and positioning identity), which are intrinsically linked to their Balancing Framework. A triad of influencers act as facilitators and barriers when positioners allocate positions to people living with dementia both pre and post Delivery. The triad may facilitate or bar access to the central ‘positive core’ of the Balancing Framework. A triad of internal requirements act as facilitators and barriers for people living with dementia when being allocated positions by others. The triad may facilitate or bar the position from achieving the central ‘positive core’ of the Balancing Framework. Positive positions are accessed through two ingresses, which denote a hierarchy of conceptual themes and sub-themes regarding their accessibility for positive positioning. Second ingress conceptual themes and sub-themes are less likely to be accessed by positioners with non-adaptive positioning identities, as positions are allocated within the confines of their emotional and practical experience. AI, through Delivery, provides all positioners with access to both the first and second ingress, although this access may still be denied by individual positioning identities.

The following chapter will discuss how the findings addressed the original aims of the thesis.

Chapter 9

Discussion

9.0 Introduction

This chapter begins by considering the contribution to knowledge of this thesis and an overall summary of the findings. The findings are then considered by addressing the individual research questions originally presented in Chapter 1, within the context of the AI principles and the scoping review presented in Chapter 3. Through a consideration of the thesis synthesis presented in Chapter 8 applied to previous research findings from Chapters 4 to 7, recommendations are presented for research, policy, practice and education. Limitations of the thesis are discussed and the thesis reaches its conclusion. This chapter includes reference to the frameworks and models developed throughout the discourse. The highlighted frameworks and models represent the theoretical developments within the thesis, which are products of the adaptations made to the AI cycle (Cooperrider & Whitney, 2001). The adaptations made to the AI cycle also represent a profound theoretical development as AI was successfully established as having generative and transformative power even when the subjects of change were not part of the original inquiry. The interconnected process (Figure 58) between positioner, narrative statement and person living with dementia is a key theoretical development. Each framework within this model is supported by the theoretical findings although it is their integration which provides the complete journey between positioner and positioned person. As far as this author is concerned, no other model has been previously developed to understand the experiential and internal factors key to experiencing positive positioning for people living with dementia. The Balancing Framework (Figure 26) potentially represents the most crucial theoretical development. The Balancing Framework represents, as far as this author is aware, the first attempt to create a positioning theory analysis tool for discrete contexts of discourse. The theoretical underpinnings for the Balancing Framework have illustrated how the experiences of negative and positive positioning for people living with dementia cannot only be defined but also analysed and visually presented within thematic contexts. The Balancing Framework illustrates a new approach to positioning theory analysis, which was crucial to the analysis within this thesis but also provides a theoretical template for further positioning theory research about dementia and other subjects. The contribution of the thesis and a summary of its findings will now be considered.

9.1 Contribution to knowledge

The design and outcomes of this study provide original and novel contributions to the field of qualitative research. Approaching AI as a mechanism for people living with dementia to share experiences and desires, leading to the design of a practical outcome, provided an in-depth understanding of the lived experiences of people living with dementia in the context of positioning theory, in relation to both prior experiences and the people living with dementia's ideal vision of society's positioning of people living with dementia. The study makes an original and significant contribution to knowledge about AI, by illustrating how the methodology can inform the design of practical outcomes by people living with dementia, which when delivered to other members of society, can influence the discursive behaviour of these new participants. The discussion argues that the principles of AI can still be observed during the process, despite the radical reconfiguration of the inquiry. The thesis contributes a theoretical development of the AI cycle (Cooperrider & Whitney, 2001) by illustrating its transformative potential with individuals outside of the original inquiry

An original contribution is made to the field of positioning theory through the development and presentation of a Balancing Framework (Figure 26), informed by the narratives of people living with dementia during AI. This is then illustrated as practically applicable for the analysis of group discourse within the context of fixed positioning themes. The Balancing Framework is a crucial theoretical contribution as the first positioning theory analysis framework to visually present allocated positions as a means to assess the contribution of the AI film towards the allocation of positive positions. A further original contribution to positioning theory is observed in the development and presentation of 5 positioning identities, which through synthesis with the contributions of people living with dementia during AI, are illustrated in an explanatory framework (Figure 57) as potential barriers and facilitators to achieving the positive discursive positions advocated by people living with dementia in the AI outcome. An interconnected model (Figure 58) illustrating the journey of discourse in positive positioning represents a key theoretical development in understanding individual experiences of positioning.

9.1.2 Summary of findings

The findings of the thesis were presented in detail in chapters 4, 5, 6 and 7. The findings were described in four key conceptual findings, which also underpin the methodological testing of the reconfiguration of AI. Collectively, the findings illustrate that people living with dementia can be supported through an AI approach to develop a mechanism, which influences the discourse of other members of society.

Through a reconfiguration of the 4D cycle of AI (Cooperrider & Whitney, 2001), the experiences of people living with dementia led to the identification of external and internal requirements for people living with dementia to experience positive positioning. The development of the internal requirements illustrate that the experience of positive positioning is not only dependent on the discourse of other members of society but also an independent internal self-positioning, which results in the personal acceptance or denial of the allocated position.

Through the process of Dream, 6 conceptual themes (A change in understanding *(about dementia and me),* Acceptance, What I can do, Who I am, Language, Ourselves) were co-created to illustrate the verbal positioning of people living with dementia in an ideal world. Through Design, people living with dementia successfully created a short film to share their experiences and advocate for change in society regarding their verbal positioning by others. These processes informed the first conceptual finding: people living with dementia are empowered to identify the requirements for positive verbal positioning using the Discovery, Dream and Design phases of AI.

A thematic analysis uncovered four conceptual themes (Belonging, Able, Supported, Dementia Unseen), which illustrate the context of the positioning experiences and desires shared by the people living with dementia, encompassing both desirable and undesirable positions. These positioning themes were validated through a Balancing Framework (Figure 26), which was successfully applied to analyse the discourse of natural discussion groups. These outcomes were illustrated in the conceptual finding: Four positioning themes as a framework to assess how people living with dementia experience verbal positioning by others.

The reconfiguration of AI occurred as the outcome of the Design phase was presented to 3 natural discussion groups. The discourse of these groups, analysed using positioning theory, illustrated that change had occurred and had therefore been Delivered. The outcomes in this phase were illustrated in the conceptual finding: Verbal positions that are directly influenced by the outcomes of AI.

Three conceptual themes (Practical experience, Emotional attachment, Positioning identities) as indicators of susceptibility to influence during discourse were developed using Bamberg's (1997) positioning level analysis The final theme was analysed further to produce 5 positioning identities (Stagnant, Open, Empowered, Threatened, Reluctant). These identities correspond to the ephemeral qualities of positions as identities are observed to vary during discourse. The variance in positioning identities illustrates the ability of all speakers to engage in positive positioning, as defined by people living with dementia, although the frequency and capacity to Deliver positive positioning is individually diverse. These outcomes were illustrated in the finding: Five thematic positioning identities as facilitators and barriers to positive verbal positioning as defined by AI.

The four conceptual findings informed a synthesis, which produced a narrative framework (Figure 57) which hypothesises that all speakers may access and accept the AI outcome to influence their positioning of people living with dementia, although positioning identities and experiences will facilitate or bar this access. The reconfiguration of AI does support positive change in participants outside of the initial inquiry although the AI outcome alone, may not overcome experiential and ephemeral identity barriers.

Through the period of completing the thesis much has changed. Whilst the original focus of the thesis was to test the methodological reconfiguration of AI, which was successfully illustrated, the depth of findings in other areas of the thesis was initially unforeseen. The AI methodology was chosen for its potential to empower participants and whilst positioning theory was crucial to the design of the thesis, the findings concerning this theory are testament to the contributions of the people living with dementia and the empowering qualities of AI.

9.2 Can AI support people living with dementia to define a lived experience of ideal verbal positioning by others?

The AI methodology was chosen for this thesis due to the supporting evidence suggesting its greater generative capacity over problem solving methodologies in research (Bushe & Paranjpey, 2015; Paranjpey, 2013). The participants did not engage with this thesis in the belief that their visioning of an ideal future would be made a reality through the research process but accepted the process of AI as a generative, rather than predictive, inquiry. Younger people living with dementia engaged with three phases of the inquiry to define an experience of ideal verbal positioning, not in the belief that they were predicting the future but because it empowered them to envision what the future could potentially be. How AI supported the vision of ideal positioning with people living with dementia can be observed in the applicability of the five AI principles (Constructionist, Simultaneity, Poetic, Anticipatory, Positive Principle) to this inquiry.

The ideal vision was developed through the phases of Discovery and Dream, and shared through Design. The appreciative narratives shared by three of the participants during Discovery included experiences of being respected for their abilities following their diagnosis. This respect was considered extraordinary because it occurred after they had received a dementia diagnosis, when prior to the diagnosis it would have been expected.

Respect for a person’s abilities may have also been more pertinent for this group who due to their younger age were more likely to perceive their identities by losses experienced in their employment and relationships (Greenwood & Smith, 2016; Harris & Keady, 2009). Whilst Vickers (1964) considered appreciation to be an unconscious process driven by perception, it is unclear whether the narratives were chosen by the participants to consciously share how their perceptions of expected positioning had changed since diagnosis or whether this was an unconscious perception that the provision of respect was now perceived as extraordinary. Whether an unconscious or conscious process, the act of Discovery supported the positive principle of AI, as participants were able to identify positive images from their own experience to inform a positive vision for the future. Participants became positive visionaries (Ludema, Wilmot & Srivastva, 1997), with the contributory factors for positive positioning identified during Discovery, applied to a vision of the ideal future.

AI provided a platform for the group to work collaboratively, despite differences in the individual perspectives of the group. For example, Sue (see section 4.2) struggled to perceive a positive experience due to her own unconscious perception that she had not met the requirements to command respect. Internal requirements for positive positioning, defined through the inquiry, identified a person living with dementia’s self-respect as integral for the ideal vision. The sharing of positive experiences by other members of the group provided Sue with a conscious understanding of her own self-positioning, which she then rejected and moved to a conscious positive vision. AI therefore emancipates the human experience, allowing those who are consciously persecuted by others and unconsciously persecuted by themselves to reject inhumane experiences, demand social justice and perceive the social actions to create an ideal future. The principle of simultaneity can be observed in the earliest phases of AI as the discourse in Discovery resulted in observable change in the self-positioning of participants. By recognising the internal requirements for positive positioning, participants recognise their own deficit based self-positioning and adjust to an appreciative stance. This experience aligns to Cooperrider and Srivastva's (1987) rejection of Vicker’s (1964) proposal that appreciation should focus on what should change, but should embrace the mystery of the subject of inquiry and value the best of what already exists, to envision a greater future.

The thesis tested the applicability of the AI framework when engaging with people living with dementia. The poetic principle of the methodology supports people living with dementia to embrace the past, present and future to interpret experiences and visions for the future. To illustrate this further, Sue had no perception of a positive post diagnosis experience but the creative possibilities of the methodology allowed a reconfiguration of the positive question, using her pre-diagnosis experience and empowering her engagement with the process. Although participants had diverse employment backgrounds, they all used employment to envision their positive narratives, underlining the importance of this subject to younger people living with dementia.

The reconfiguration of the AI phases, with people living with dementia uninvolved in the change process, following Design does not deny the presence of the anticipatory principle. As simultaneous changes in perception are observed through discourse, the anticipation of a better future is directly observed when people living with dementia envision this ideal future. The acknowledgement of internal requirements also provides a basis for behavioural change that may provide greater access to positive self-positioning and experiencing positive positioning by others.

Whilst people living with dementia may not share the same experiences and may vary in their beliefs of what an ideal future would include (e.g. Gavin insisted that people living with dementia should share their diagnosis with other members of society, whilst other people living with dementia suggested that they should not have to), the AI methodology empowered them to employ all points of view within the defined outcome of a short film. The constructionist principle is embraced by people living with dementia who share their own perspectives but elevate the inclusivity of all perspectives in the visioning process. Despite the different individual perspectives, the views of all people living with dementia aligned to findings from the scoping review, suggesting that people living with dementia do not view dementia as something to be ashamed of (Hedman, Hansebo, Ternestedt, Hellström, & Norberg, 2013). However, this finding in the scoping review is inconsistent with Johannessen et al's (2018) suggestion that younger people living with dementia are more likely to conceal their diagnosis rather than share it. Although the younger people in this study did not always want to share their diagnosis, this was due to a belief that the diagnosis should not influence how they were treated rather an attempt to conceal it. The act of creating the AI film to share their vision is a clearer indication that these younger people did not want to conceal their diagnosis. Whilst the core of the film was the positive vision, it was built from a belief that the experience of younger people living with dementia is not universally positive. This is consistent with Page and Keady's (2010) suggestion that young onset dementia is particularly distressing and life altering, which contributes to younger people wanting to publicly share their experiences of dementia. McNamee and Gerge (1999) argue that approaches to inspire new ideas depend on inclusion and people living with dementia were observably empowered by the inclusive approach of AI to inform their visions for the future.

This appreciation of shared narratives provides the generativity for co-creation, which supports the critical humanist perspective of the thesis. Whilst people have individual experiences, they do not exist independently but share discourse, which creates a conscious empathy (Kozlarek, 2020). The appreciation of each person's narrative empowered people living with dementia to empathise with each other's diverse experience of living with dementia, resulting in a co-ordinated demand for social justice and action (see section 4.4). Critically, accepting the findings of this thesis is aligned to accepting critical humanism and therefore accepting the experience of dementia as narrated by people living with dementia. Through AI, people living with dementia share their experiences, allowing their peers and others to recognise their humanity. Through AI, people living with dementia used Design to create a tool to support others to reject inhumane practices.

The political context is clear that the social stigmatisation of people living with dementia needs to be urgently addressed (Batsch & Mittelman, 2012a; Department of Health, 2015; Welsh Government, 2018; World Health Organization and Alzheimer's Disease International, 2012). This study proposes that addressing social stigma is not only about identifying what is wrong in society but also about having a clear vision of what it should be. The AI process has supported people living with dementia to define their ideal world, moving away from an allusively defined world without stigma to a clearly articulated vision of stigma-free discourse relating to people living with dementia. The thesis supports Swaffer's (2014) proposition that 'dementia-friendly' language may be used to disguise stigmatising attitudes and beliefs and proposes that the positions advocated by people living with dementia through AI, deny the availability of a dementia friendly pretence during discourse, without the supporting social beliefs and behaviours.

The vision of the future proposed during the AI process shares a significant alignment to the findings of the scoping review presented in chapter 3. The identification of internal requirements acknowledges that people living with dementia may also position themselves, and subsequently other people living with dementia, negatively. The literature supports a change in self-positioning, with people living with dementia referring to themselves as no longer of use, fit for the rubbish bin (Langdon, Eagle & Warner, 2007) and the 'living dead' (MacRae, 2010). The internal requirements identified by people living with dementia during AI are intrinsic to their vision of the ideal world. People living with dementia who negatively self-position themselves, will be less open to positive positions offered by other speakers. Sue's movement from negative self-positioner to being empowered to demand positive verbal positioning for all people living with dementia, indicates the simultaneity and anticipatory principles of AI as catalysts for this change.

A significant focus of the ideal world was aligned to people living with dementia's desire to have their abilities acknowledged and respected. A current lack of positive positioning was observed in the *practical ability* domain during the scoping review, which illustrated no occurrences of people living with dementia perceiving the allocation of a positive position about their current abilities but regularly positioned within the themes relating to *lacking ability* and being *dependent* (on others). The example from the literature of the person living with dementia attempting to reposition themselves, in respect of their ability: 'I am a lawyer' (Sabat & Harre, 1992) is similarly observed in the narratives of the people living with dementia who all appreciated respect for their vocation during their Discovery narratives. The application of vocational ability as an indicator of accomplishment aligns with Österholm and Samuelsson's (2015) assertion that people living with dementia will attempt to reposition themselves as competent, if positioned negatively. Previous literature has suggested that people living with dementia position themselves as knowledgeable but are aware of their cognitive limitations (Sabat, Napolitano, & Fath, 2004). Similarly, people living with dementia engaging in AI did not eliminate their dementia diagnosis when envisioning an ideal world but focussed on what they could do, whilst acknowledging the importance of family (Colin), friends (Pauline) and colleagues (Sue and Gavin) for their support (see section 4.2).

The ideal world's acceptance of the people living with dementia's choice about what they chose or chose not to do, ran through several themes within the Dream developed during AI, with participants suggesting that they would be more likely to engage if the decision was not made by somebody else. Small et al (1998) observed that when people living with dementia were allocated depersonalising positions, they would be less likely to co-operate but would be more co-operative when the person living with dementia was positioned as independent. Younger people living with dementia have also indicated a tendency to socially retract if they feel unable to cope with the behaviour of others (Johannessen et al, 2018). As social citizenship is defined by how others reciprocate a person's place in society (Hopkins, Reicher & van Rijswijk, 2015), the younger person's citizenship is supported here by the other's acceptance of them wanting to be alone rather than 'socially' active.

To the uninitiated, an ideal world could suggest a vision of unreachable utopia but a central aspect of the people living with dementia's vision was to be treated as 'normal'. People living with dementia in the literature have also been observed using similar positions in other research, with some describing themselves as 'average' (Clare & Shakespeare, 2004) and 'ordinary' (Godwin & Poland, 2015). Whilst AI did empower people living with dementia to define a lived experience of ideal verbal positioning by others, the ideal world did not demand extraordinary positions but a return to an ‘ordinary’ human experience of pre-diagnostic positioning.

9.3 Can the outcomes of an AI cycle with people living with dementia influence the verbal positioning of other groups in society?

The theories of malignant positioning (Sabat, 2000) and malignant social psychology (Kitwood, 1997) are tied to the latter author’s proposal that people living with dementia are not visible or heard in society. The creation of a short film through AI, directly presented the desires of people living with dementia to other members of society, which resulted in an overall change in how these groups positioned people living with dementia in subsequently analysed discourse. Vicker’s (1964) proposal that appreciation occurs through perception indicates that hearing the voices of people living with dementia led to a change in their perception of people living with dementia once the group members were introduced to the AI outcome, resulting in positions aligned to positive rather than malignant perceptions of people living with dementia. For example, when Beryl’s case study was presented (see section 6.2), people living with dementia had no presence in the discourse beyond the presented case and a greater number of negative or malignant positions were allocated. The AI outcome provided a perception of people living with dementia through their human narratives, which was followed by increased allocations of positive verbal positions. AI’s principle of simultaneity was observed as group discourse about the individuals within the film, led to a simultaneous positive change in their positioning of the people living with dementia presented in the natural discussion groups. This principle was also observed in the positioning by one lay person who, following the AI film, attributed positions suggesting capability to Sally and her husband in the belief that they may be younger people living with dementia. For this participant, the age group of the people living with dementia in the AI film has narrowed this simultaneity to include age as well as diagnosis. This could enhance the social citizenship of younger people living with dementia but could also potentially result in older people being regarded as unequal to their younger counterparts.

A core element of malignant positioning is that people who find themselves positioned in a manner which is objectionable to them, often find their attempts to reposition themselves are rejected (Sabat, 2003). This positioning was observed in the scoping review domain, *Control over life* and the theme, *diminishing control*. Positions allocated by healthcare workers: ‘I’m in charge not you’ (Sabat et al, 2014) counter those allocated in other literature by people living with dementia in the literature, who position themselves as being able to say what they like or dislike (Batra et al., 2015; Bourbonnais & Ducharme, 2013). Discourse concerning Beryl’s case study led to all three groups advocating her attendance at a day centre, without the consideration of whether she wanted to attend. Beryl's continued activity was considered dependent on the actions of others, which also aligned to the scoping review sub-theme of dependent in the practical ability theme. Beryl was positioned as requiring support to shop and travel, despite no supporting evidence that she needed this support, similar to positions in the literature that people living with dementia require support to maintain their roles (Purves, 2010). Following the AI outcome, Sally's case study led to positions, which focussed more on her ability to choose her activities, as the narratives of the people living with dementia from AI informed the positioning of other people living with dementia. This aligns to the poetic principle of AI as the natural discussion group members applied a human interpretation of the narratives in the AI outcome to their discourse about the case study.

The movement from malignant positioning to positive positioning also aligns to the positive principle of AI. Whilst the responses to Beryl's case study led to deficit based positions, Sally's case study led to responses, which denied the deficit based approach. These positions supported Sally to negotiate her needs with health services, advocating for her participation in deciding the level of care she required and when she would request this. This negotiation and participation supports the person with dementia's status as a citizen (Barnes and Brannelly 2008). Without the AI outcome, assumptions of incapability were accepted but the introduction of AI supported participants to look for the best of what is. Similarly, the anticipatory principle supported a non-deficit based approach to suggestions of potential interventions post AI.

AI supports people living with dementia to challenge malignant positioning, although Sabat's (2003) proposition that only caregivers can reverse malignant positioning can also be achieved through the AI process, as healthcare workers in the natural discussion groups actively challenged the assumptions of incapability made by other group members following the AI film. The AI outcome influenced the positioning of people living with dementia but also empowered natural discussion group members to challenge malignant positions offered by other group members.

The allocation of the Dementia Unseen theme in the 2nd ingress of the narrative statement framework (Figure 57) indicated the lack of movement from negative to positive positioning within this theme following the AI outcome. Family members/carers are less open to the influence of AI regarding this theme. Sabat (2019) observed that people living with dementia whose dementia is considered their principle attribute, are treated uncivilly. The family member/carers group's initial discourse following the AI film was to discuss ranking the people living with dementia in order of severity of cognitive impairment. The perceived younger age of one participant was used by one family member/carer to support their perception that they were ‘better’ than the others, although this was disputed by other members of the same discussion group. The thesis’s critical humanist perspective must regard this as a failure of the AI process as the classification of people by cognitive ability is inhumane in this context. Similar failures are observed regarding the sub-theme, *Superior,* with very few positive positions allocated following the AI outcome.

The Superior sub-theme was central to positive positioning in the narratives of people living with dementia, with experiences tied to vocational skill featuring in all shared experiences. As the group was made up of younger people living with dementia, the focus on vocational skills is aligned to previous suggestions that this younger cohort may view their vocation as integral to their identity (Greenwood & Smith, 2016; Harris & Keady, 2009). The lack of positive positioning following the AI outcome is aligned to the lack of literature regarding vocational contributions of people living with dementia in society (Ritchie et al, 2015). Research in this area has tended to focus on the deficiencies in people living with dementia’s vocational abilities, the lack of adjustments for these deficiencies and the effect on co-workers (Chaplin & Davidson, 2016; Ohman, Nygard, & Borell, 2001). Thomson et al (2019) described an absence of research narratives detailing the positive contributions of people living with dementia in employment. As a younger person living with dementia, Gavin’s narrative directly challenges this absence as he described an ongoing experience of positive employment. The lack of positive Superior positioning could also be attributed to the Sally case study narrative, which did not provide a narrative to instigate this positioning.

The AI outcome altered how the recipients perceived people living with dementia. The critical humanist stance suggests that changes through education should be observable in real life situations (Lekoko, Suping, & Pitso, 2018). Whilst changes in the positioning of case study exemplars may be dismissed as merely academic from the critical humanist perspective, the changes in positioning were also observed to affect real-life relationships. The increased positive positioning of people living with dementia in all groups aligns to the constructionist principle of AI. Hearing the voices of people living with dementia uprooted the assumptions of group members who co-constructed their understanding of positive positioning for people living with dementia. McNamee and Gergen's (1999) theory of ‘relational responsibility’ which, views this construction as a collective process, rather than driven by individuals, aligns to the behaviour of the healthcare workers who rejected individual members who did not align themselves to the positive collective view of the future.

AI, when reconfigured to support people living with dementia, to demand changes in the allocation of verbal positions by other society members was observed to successfully meet this requirement within certain contexts. However, the degree of movement from malignant to positive positioning varies between contextual themes and the influence of individual traits of the positioner.

9.4 What factors influence the verbal positioning of people living with dementia by members of society aware of the AI outcome?

There is an interdependence between the phases of AI to not only envision the ideal future but also take actions to move towards it. By reconfiguring the process of AI to include different participants between phases, this study proposes that this interdependence does not only apply to the phases of the process but also the varying participants. More importantly, the study proposes that this interdependence can successfully result in the acceptance of a co-created vision resulting in defined changes, aligned to the positive vision. The variability in the positioning of people living with dementia by individual participants is consistent with other AI, and change based, literature suggesting that involvement in a change process does not necessarily lead to consistent behavioural changes (Bovey & Hede, 2001; Lazic et al, 2011).

This study proposes that there is a dynamic relationship between the voices of people living with dementia and other society members, and whilst stigma concerning dementia is socially constructed, individuals are able to remove their positioning from that construction if they are open to change. The study identified two experiences (emotional and practical) and five positioning identities that acted as barriers and facilitators to accept the views of people living with dementia to inform individual behaviour. These findings are aligned to theories about other transformational change models where attitudes and beliefs of participants are regarded as key elements for successful change (Chapman, 2002). It is these factors which the study proposes, are central to the inter-dynamic between people living with dementia during the first stages of AI and other participants. Accepting the narratives shared by people living with dementia leads to an agreement of how people behave and what is accepted as possible. When participants accept these narratives, changes are aligned to the principle of simultaneity leading to an empowered positioner, who is inspired to advocate for social justice.

The study's identification of positioning identities shares similarities with the five factor model of personality (Briggs, 1992; Goldberg, 1990; McAdams, 1992), particularly in the factor of openness (the appreciation of new experiences), which is congruent with the varying identities descriptions of openness to the AI outcome. This study also proposes that the AI outcome contributes a new positioning identity, that of the *empowered positioner*. Whilst other identities are informed by prior experiences and beliefs, the empowered positioner identity is only available to participants who have engaged with the AI outcome. This identity does not exist for any participant until they have engaged with the AI process and whilst having this identity continues to support the allocation of positive positions, it also empowers participants to challenge the non-positive positions allocated by other group members.

The transformation to positive positioning is central to the vision shared by people living with dementia during the AI outcome, whilst the transformation in the positioner's identity confirms the continued applicability of the constructionist principle (as participants from different phases of the process embrace a shared vision) and AI's ability to empower. There is a wealth of supporting research detailing the empowering possibilities of AI (Clossey, Mehnert & Silva, 2011; San Martin & Calabrese, 2011; Dewar et al, 2020) but this study proposes that empowerment is possible for participants, even when they have not engaged in all four phases of the process, but at the same time, all four phases are completed.

Loss of function and independence, aligned with older age, have been observed as the main causes of stigma towards people living with dementia in Western society (Cipriani & Borin, 2015). The inclusion of younger people in the AI film potentially does not discourage the denial of social citizenship for older people living with dementia. However, only one lay person used younger age as a quantifier for their positive positioning following the film. Positions concerned with functioning were addressed in the *Able* theme. In all three natural discussion groups, the discourse prior to viewing the AI outcome positioned people living with dementia less positively regarding their functional abilities. The assumption that the people living with dementia in the case study was less functionally able than a person without dementia informed this positioning. The outcome of social stigmatisation is being perceived as different (Rewerska-Juśko & Rejdak, 2020) and here, people living with dementia are immediately regarded as different due to assumed functional changes. Whilst the family member/carer and lay people group allocated greater number of positive positions, following the AI outcome for this theme (see sections 6.4.2 and 6.4.3), the healthcare worker group observed minimal change (see section 6.4.1). This positioning by healthcare workers is consistent with the scoping review findings when only 10% of positions allocated within the *practical ability* domain were related to *current ability*, rather than positions concerning lack of ability. The study proposes that it is the overwhelming practical experience of healthcare workers that informs this non-positive positioning. Whilst positive positions in the first case study discussion had a higher occurrence (22%), there was minimal change in the case study discussion following the AI outcome (24%). Three health care workers did provide a greater number of positive *Able* positions (HWA, HWB, HWD). Whilst this change can be observed as evidence of the dominant positioning identities in two participants (HWB: Open, HWD:

Empowered), it is also inconsistent with HWA's dominant stagnant positioner identity. Despite these exceptions, the minimal positive change in this theme appears to align with the practical caregiving of healthcare workers, whose positioning remained overtly influenced by their experience of dementia care, rather than the AI outcome.

Similarly, family members/carers saw no positive change within the *Dementia Unseen* theme following the AI outcome, with the act of ranking the people living with dementia based on their perceived degree of cognitive and functional impairment, consistent with positions in the literature, which perceive people living with dementia as *worthy of derision* (Arieli, 2013; O'Shaughnessy et al., 2010). Although the study does suggest an alignment between the emotional attachments of family members/carers and the practical experiences of healthcare workers as crucial positioning influences, this is not to deny that both groups have emotional and practical experiences of dementia. However, research about the emotional impact on healthcare workers caring for people living with dementia is currently limited (Bassal et al, 2015) and has also tended to focus on the emotional burden of dementia on families (Bruvik, Ulstein, Ranhoff, & Engedal, 2013; Rabins, Mace, & Lucas, 1982) or interventions to relieve burden (Hurley, Patterson, & Cooley, 2014; Schoenmakers, Buntinx, & DeLepeleire, 2010).

The study is validated in its proposition that the emotional and practical experiences of these two groups act as barriers to achieving as positive positioning, through the substantial positive change observed in the lay people group (see section 6.4.2). For example, the practical experience of LPB, a retired healthcare worker, is also observed in her positioning of people living with dementia, retelling the narrative of a woman who 'put her knickers in the microwave' on three occasions to inform her positioning of other people living with dementia. This discourse is aligned to similar narratives shared in the scoping review about people living with dementia, such as 'lost in the shops and you still had your gown on' (Adams & Gardiner, 2005). Here, the position of the people living with dementia is based on how their behaviour is inconsistent with social norms, rather than the identification of an unmet need.

Critical humanism demands we push participants to accept and enact the positioning ideals advocated by people living with dementia through AI. However, taking this stance also demands that we respect the individual experiences of all participants. Whilst experiences and positioning identities provide an understanding of why some people may be more likely to embrace the vision of people living with dementia, it is vital that we do not place any human into a concrete category, suggesting that they are the same or different to others (Anderson et al, 2010). The factors which influence the verbal positioning of dementia are not fixed, nor should they be judged with quantifiers such as right and wrong. A participant identified as a threatened positioner, who does not embrace the vision of people living with dementia, does not necessarily choose this outcome for themselves but is already entrenched in their own experiences.

To adopt this stance further, it is crucial that the human experience of participants in the natural discussion groups is also acknowledged and accepted. Through the recognition of positioning identities, the diverse experience and humanity of these participants is recognised. Although discourse moved closer to the positive positions advocated by people living with dementia, non-positive positions continued to be allocated. Positions antithetical to the vision of positive positioning are aligned to previous theories regarding malignant positioning (Sabat, 2000), which potentially result in malignant behaviours (Kitwood, 1997). However, neither malignant positioning nor malignant social psychology are perceived as deliberately abusive, as people may engage with these behaviours without ill intentions. Natural discussion group members who allocated non-positive positions did not deliberately avoid allocating positive positions but were individually influenced by their lived experiences and their evolving positioning identity. Through AI, greater numbers of positive positions were allocated, but incidents of continued negative or neutral positioning should not indicate a malevolent position for the speaker. Instead, the positioning identities provide another example of humanity and the human experience.

This study agrees that AI has great generative potential and as a mechanism of change it can be transformational. The study proposes that to influence the allocation of positive positions it is crucial that we first understand what people living with dementia consider positive positioning to be. Through the first phases of AI, people living with dementia were able to define a positive vision of the future. The study aligns itself to Sabat's (2003) proposition that only caregivers can reverse malignant positioning by suggesting that it is only the discourse of other members of society that can truly transform the experiences of discourse for people living with dementia. Whilst the influence of the AI outcome on discourse is dependent on practical, emotional and identity factors of positioners, it can influence all participants to varying degrees, to envision and enact positive discourse about people living with dementia.

Researchers who are reluctant to use AI due to fears that people living with dementia may be unable to identify positive narratives should draw on the example of Sue in this thesis. Sue initially struggled to identify a positive narrative but the democratic support of the group aligned to the creative malleability of AI encouraged the sharing of positive experiences. The movement from deficit based thinking can be challenging and Sue's difficulty in identifying a positive narrative should not lead to conclusions that AI may be more problematic for people living with dementia. Difficulties in identifying positive narratives are acknowledged by AI with Cooperrider and Whitney (2005) suggesting that dreams and aspirations should be used when a lived positive narrative is lacking. The concept of living well with dementia shares AI's movement from deficit based to positive thinking. Living well with dementia encourages inclusion, participation and the person's optimal use of their abilities (Clare et al, 2019). As living well with dementia has been described as a subjective contentment with life (Department of Health, 2009), the inability to identify positive experiences is attributed to the subjective internal experience of the person living with dementia (see 8.2.4). By challenging Sue's negative perception of herself, AI emancipated her positive experience to contribute an understanding of personal narrative citizenship, which then advocated positive social citizenship through the AI film. Whilst people do live well with dementia, there are low points in everyone's journey (Bartlett et al, 2017) and whilst AI focusses on the positive it does not deny the existence of negative experiences. The struggle to identify positive experiences is indicative of the negative impact dementia has had on people's lives but researchers must continue to embrace positive narratives to understand the subjective experience of living well with dementia.

9.5 Younger people living with dementia

The thesis focussed on the applicability of AI when used with people living with dementia. The inclusion of younger people living with dementia was not a deliberate attempt to focus on this particular cohort but rather an outcome of the group who consented to the study. The experience of dementia for younger people has been associated with more distressing psychosocial issues as well as a lack of appropriate services for this group (Pijenburg & Klaassen, 2021; Roach, Bee & Keady, 2021). The aims and findings of the study are now considered in the context of this younger age group.

9.5.1 Can AI support younger people living with dementia to define a lived experience of ideal verbal positioning by others?

The narratives shared through Discovery were crucial in the eventual formulation of an ideal world. All four younger people living with dementia identified narratives concerning employment to illustrate positive positioning. Employment is often the first aspect of the younger person's identity to be fragmented following their diagnosis (Harris & Keady, 2009) and this potentially indicates why these narratives were chosen. This fractured identity is most clearly illustrated in Sue's narrative as she drew upon a pre-diagnosis experience to identify positive positioning. Equally, Gavin's narrative denies the assumption that this fractured identity occurs in the experience of all young people living with dementia as his was an ongoing narrative of feeling positively positioned in his employment. Bartlett (2014) suggested that the absence of employment in younger people living with dementia may be replaced by advocacy, resulting in their continued active citizenship. For these younger people, their positive experiences were aligned to paid employment and the ideal world accepted their active citizenship, without any recommendations concerning ongoing needs for advocacy.

The concept of an ideal world designed by younger people living with dementia did not focus on their age. The ideal world was created without allocating people into younger and older age brackets. Their ideal world advocates the social and relational citizenship of all people living with dementia, through a vision of equality and belonging. The Dream theme 'Who I Am' included the factor: *We are not instantly all seen as an old person in a nursing home* (see 4.3). This factor was the only part of the Dream, which indicated a consideration of age as relevant to the ideal world. In the larger context, however, this factor was used to support an ideal world where people living with dementia were active citizens and the imagery used here was to deny their positioning as inactive and invisible to society rather than an attempt to position older people negatively. Although the experience of younger people living with dementia is considered more distressing (Pijenburg & Klaassen, 2021), this group of younger people did not envision a unique position for younger people in their ideal world. In their ideal world, all people living with dementia were positioned equally, regardless of their age.

The ideal world also supported people living with dementia to choose to be inactive without being positioned as problematic. Younger people living with dementia have been noted to avoid social situations, which potentially results in them being socially excluded (Greenwood & Smith, 2016). In the ideal world, choosing to exclude oneself does not result in social exclusion by others. This aspect of the ideal world is aligned to effective citizenship, which views people as effective citizens even if they do not want to participate (Bartlett, 2014). The ideal world also envisioned respect for people living with dementia's citizenship in healthcare provision. This citizenship has been described as being about negotiation and participatory relationships (Barnes & Branelly, 2008) although for these younger people, this citizenship is simply described as being treated like 'anybody'.

9.5.2 Can the outcomes of an AI cycle with younger people living with dementia influence the verbal positioning of other groups in society?

The findings have indicated that the AI film has influenced a change in the verbal positioning of people living with dementia in other groups (see Chapter 6). The younger age of the people living with dementia is rarely mentioned by the discussion groups although LPE does use younger age to support her positive positioning after viewing the AI film (see 6.3.2) LPE's positioning indicates a perception that the experience of younger people living with dementia is different to their older counterparts. As the position is built around the assumption that the needs of younger people may be different, it aligns to criticisms of current services, which are built for older people and therefore unsupportive of younger people's needs (Giebel et al, 2020; Rabanal, Chatwin, Walker, O'Sullivan & Williamson, 2018; Roach, Bee & Keady, 2021). However, the use of age to support a position of needs may also contribute to concerns that age specific services deny access to those who may need them (Pipon-Young et al, 2011). The denial of participation, without an ability to negotiate, denies the person's social citizenship (Barlett & O'Connor, 2010) indicating that the position is positive within the context of the ideal world advocated by younger people but may deny aspects of citizenship for older people.

Driving cessation has a greater impact on younger people living with dementia (Velayudhan et al, 2018). LPE used Sally's continued ability to drive in the case study to indicate her younger age (see 6.3.2). Although this assumption could be attributed to the content of the case study aligned to the younger people in the AI film it is actually consistent with other participant's statements regarding older people and driving. The cessation of driving in older age is regarded as a normal activity, outside of the context of dementia, indicating that verbal positioning regarding this ability is influenced more by the practical experiences of the participants than the AI film.

9.5.3 What factors influence the verbal positioning of younger people living with dementia by members of society aware of the AI outcome?

Different dementia diagnoses often result in differing emotional responses towards the person by other people (Diefkuss, De Larwelle & McFadden, 2018). Although each younger person shared their diagnosis in the AI film, there was no evidence in the discussion groups that this was used to influence their verbal positioning. Gavin's diagnosis of fronto-temporal dementia is more typically observed in younger people. Media representations of fronto-temporal dementia mean that people with this diagnosis are more stigmatised against, compared to people with other dementias (Nair & Dubljevic, 2021). An acceptance of social citizenship for younger people living with this diagnosis is crucial to overcoming this stigma. Gavin's contributions during AI are a mechanism to influence this acceptance through narrative citizenship as he locates himself in the social world (Clarke & Bailey, 2016). In the context of the natural discussion groups, however, the younger people's sharing of their diagnosis had little observable impact on the positioning by others. Gavin was the only younger person living with dementia to have their specific dementia diagnosis considered by discussion group members. The family member/carers group mention his diagnosis (see

7.4.4) but its lack of impact on their positioning is illustrated as they incorrectly recall his diagnosis as Alzheimer's disease.

The factors influencing the verbal positioning of people living with dementia are illustrated in Chapter 7. As the case studies did not specify the ages of the people living with dementia, it would be assumptive to suggest that the positioning by the natural discussion groups would radically alter if this information was included. Further research in this area is encouraged in the following recommendations.

9.6 Recommendations

This thesis has contributed original research findings relating to AI and positioning theory. Recommendations regarding research, policy, practice and education are presented. Further details for these recommendations are in Appendix 10.

9.6.1 Recommendations for research

1. More research is required regarding the positive narratives of people living with dementia, including younger and older participants, as a mechanism to explore potential interventions that could support ongoing positive experiences.
2. Further explorations should be conducted to test the reconfiguration of the 4D model of AI and whether its generative and transformative potential can impact on participant behaviour in different phases.
3. The Balancing Framework has been demonstrated as a novel method of conducting and displaying positioning theory analysis. This framework should be tested further with more extensive discourse, unrelated to case study materials.
4. The Balancing Framework is a novel approach to positioning theory. Further Balancing Frameworks should be developed to analyse other lived experiences.
5. Mitigation for the barriers faced by participants to allocate positive positioning require further exploration.
6. More research is required to understand the emotional impact of caring for people living with dementia on healthcare workers.
7. A longitudinal follow-up study should address whether the changes in positioning are observed beyond the discourse of the case studies. The study should explore whether the study outcomes are also applied to real world actions to achieve social justice for people living with dementia.
8. Further AI film projects should include younger and older people living with dementia to measure the impact of the outcomes in relation to the demographics of participants.

9.6.2 Recommendations for policy

1. Younger people living with dementia have conceptualised an ideal vision of the future in relation to their positioning by members of society. Policy makers should focus on these visions when developing and applying dementia related policies.
2. AI should be applied as a means to engage with underrepresented groups to identify and design outcomes, which should be adapted to inform policy and deliver social change.
3. Policy drivers to address the social stigmatisation of people living with dementia are required.
4. Policy makers must include people living with dementia in the development and revision of initiatives. This involvement should include an appreciative stance, with involvement supporting a positive experience for people living with dementia.

9.6.3 Recommendations for practice

1. Hearing experiences of dementia through the voices of people living with dementia of all ages, is crucial for health and social care staff.
2. The voices of people living with dementia should be included in local health and social care developments.
3. The education of health and social care staff should look beyond ‘dementia friendly’ labels and consider the social impact of language on people living with dementia.
4. The Balancing Framework should be applied to consider discourse in health and social care practice.

9.6.4 Recommendations for education

1. People living with dementia should be included in the teaching of health and social care students.
2. AI should be embraced by health and social care educators to support positive reflections with their students.
3. The education of health and social care students should look beyond ‘dementia friendly’ labels and consider the social impact of language on people living with dementia.

9.7 Limitations of the thesis

The limitations of this research are generally tied to the recommendations documented in this chapter.

The scoping review was a serious attempt to collect and analyse verbal positions within the academic literature concerning people living with dementia. The scope of this review was therefore limited as other non-academic sources were not included. This inevitably means that the scoping review does not capture the full spectrum of verbal positioning experienced by people living with dementia. However, academic literature was chosen as it was through these sources that positions (or allusions to positions) could be identified rather than extracts of discourse. The identification of the latter as a means to identify positions in discourse could be attempted but would be potentially too large an area to reasonably attempt within one review. This limitation is also recognised in the scoping review included in this thesis as the creation of domains, themes and sub-themes remained large, even after several months of analysis. However, this limitation also demonstrates the complexity of considering the overall experience of verbal positioning and highlights the strengths of the more focussed Balancing Framework developed through AI.

The people living with dementia participants would all be classified as younger people living with dementia. The age of the participants was remarked upon by members of the natural discussion groups. The testing of the AI outcome would have benefited from a group with more diverse age ranges to assess whether the same outcomes would occur if older people living with dementia had been involved. Further studies should include more demographically diverse people living with dementia.

The creative approach to AI could have been tested further. The people living with dementia in the study were all in the earlier stages of dementia, although the recommendation that a longitudinal approach to the study should be undertaken means that the potential cognitive deterioration of participants should be considered. The study in this thesis could have included people living with dementia in later stages of the disease in appropriate phases of the methodology (e.g. a person living with dementia unable to contribute to Discovery due to difficulty with recall, may still be able to contribute to Dream). However, this was a novel approach to the AI methodology and the potential to be more creative with the approach does not dampen the originality of the approach in this thesis.

The development of the Balancing Framework was partially developed due to the absence of an appropriate model for positioning theory analysis. Whilst the Balancing Framework is applicable for analysis within the context of the themes of this thesis, it would not necessarily be transferable as an analytical tool for all discourse. However, the framework itself could be developed by other researchers to include other themes of interest, using the approach described in this thesis.

The identification of identities and experiences, which potentially act as barriers for positive verbal positioning was a novel finding in this thesis. From the critical humanist perspective, the thesis does not identify practical support to overcome these barriers. However, the contribution of their identification supports the recommendation for further research in this area.

9.8 Concluding remarks

This thesis presents the first study to reconfigure AI to support people living with dementia to envision their ideal experience of society and to challenge other members of society to achieve this. The thesis evolved from a standpoint that people living with dementia are being allocated harmful and unwanted positions, and are often disempowered by this position to redress this discourse. The study presented a unique insight into the experience of dementia as participants embraced the non-deficit based approach of AI to share stories, generate ideas and create a short film to share their beliefs for the future. A new Balancing Framework was developed to support the analysis of discourse using positioning theory from the contributions of people living with dementia. The short film was observed to have a transformative effect on members of three diverse groups in society, as their positioning of people living with dementia moved closer to the ideal vision identified during the first phases of AI. The exploration of allocated positions within natural discussion groups, influenced by experience and ephemeral identities led to a new model of discourse synthesis, illustrating the barriers and facilitators to adapting the discourse advocated by people living with dementia during AI. An evaluation of the aims of the thesis recognised the continuing presence of the principles of AI during all four phases of the reconfigured methodology.

This study has advanced the application of the AI methodology and positioning theory. In the context of this thesis, these approaches have been used to achieve a degree of positive social action for people living with dementia and future work should continue to focus on social justice for members of society whose voices are currently repressed.

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Appendix 1: Approval for ethics application

Ethical approval granted for 2018-16165 Discourse and Dementia

Dear Ian,

2018-16165 Discourse and Dementia: An Appreciative approach to the verbal positioning of People living with dementia.

Your research proposal number 2018-16165
has been reviewed by the Healthcare Sciences (Post-reg) Ethics and Research Committee
and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Appendix 2: Participant consent form

CONSENT FORM

Title of Project: **Discourse and Dementia: An Appreciative approach to the verbal positioning of People living with dementia.**

Name of Researcher: Ian Davies-Abbott

Please initial box

1. I confirm that I have read and understood the information sheet dated[Dated and version number] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I confirm that I consent to being filmed as part of the research process. ☐
4. .I give permission for the researcher to use anonymised quotes and for anonymised data to be shared with any other researchers or stored as data archives. ☐
5. I agree to take part in the above study. ☐

Name of Person ______________________ Date ______________________ Signature ______________________

Researcher ______________________ Date ______________________ Signature ______________________

When completed, 1 for informant 1 for researcher site file; 1 (original)

Appendix 3: Participant information sheet: People living with dementia

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Discourse and Dementia: An Appreciative Approach

Information about the study

Throughout all our conversations we take positions. These might be positions that reflect our job roles or our place in the family. Verbal positions can quickly change as one person may position themselves as clever but is then positioned as foolish when others belittle them. The ability to reposition ourselves is paramount in the way we show and uphold who we are as a person.

Sometimes, People living with dementia can be positioned as inferior or have their skills and personality ignored by others, even when that person means well. A person living with dementia may find that their attempts to reposition themselves are ignored as others in the conversation place more emphasis on their diagnosis of dementia rather than their individuality.

You are invited to take part in a research study examining whether an Appreciative Inquiry approach can be used by People living with dementia to influence how they are verbally positioned by others.

Appreciative Inquiry is an approach to change when developing a service or even society. Whilst most methods tend to focus on negatives or what doesn’t work to instigate change, Appreciative Inquiry uses positive experiences.

Current research concerning the verbal positioning of People living with dementia and has tended to dwell on negative experiences. This study aims to explore the positive experiences of People living with dementia which can be used to inform and influence the verbal positioning by others through their experience.

This is a PhD study that is being funded by the local health board.

Why have I been asked to take part?

You have been asked to take part because as a person living with dementia you have the experience and knowledge that is necessary for this research to be successful. The research team would like you to take part in an Appreciative Inquiry workshop. In this workshop you will be asked to share your experiences of being respected as a person rather than being viewed as a victim of dementia. As a group you will then be asked to use your experience to imagine what the world would be like if these positive experiences happened all the time. Finally, you will be asked to share your experiences through a video recording that will be shown to groups of people outside of the workshop. This video will form the basis of understanding whether the video created through the Appreciative Inquiry approach changed how others verbally position People living with dementia.

What does the study involve?

The study will require you to attend two sessions.

The first session will involve being part of a group with other People living with dementia. During this session you will be asked to participate in an Appreciative Inquiry. You will be asked to think of a time when you feel that you have been respected for the person that you are and not judged on your diagnosis of dementia. You will be asked to share this experience with the group. In the group you will then be asked what the ideal world would look like if People living with dementia were always spoken about and with, in a manner that is acceptable to you.

The second session will involve you telling your story again and sharing what you feel the world should be like to a video camera. You will be given help to put together a script if you want one although you can tell your story in any way you choose to. This short film will be used in the next part of the research with other groups of people.

Apart from the researcher the video you create will only be viewed by the healthcare workers, family members and lay people involved in the research.

Are there any benefits or risks?

Although you will be asked to share your positive experiences there is always a risk with any discussion about dementia that some participants may find this difficult or upsetting. In the event that you do become upset you will be supported by the researcher and provided with any signposting information that you may need.

There may be an immediate benefit to you or other People living with dementia if the research has a positive result and the verbal positioning of people who watch your video changes to become more similar to the experience described in your ideal world. However, the research is unlikely to have a substantial immediate effect but will inform the use of Appreciative Inquiry and provide valuable information about the preferences of People living with dementia regarding verbal positioning. Therefore it is hoped that there the research will have more substantial benefits for People living with dementia in the future.

What will happen to my data?

All data collected will only be accessible to the researcher and all identifiable information will be anonymised. The data from this study will be stored securely for three years. If you choose to withdraw from the study and your data is identifiable to the research team, then you have the right to request that your data is not used.

What if I don't want to take part?

It is up to you to decide whether or not you would like to participate in this study. Deciding not to take part will not impact any other aspect of your health care.

Who do I contact about the study?

Ian Davies-Abbott: Researcher, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF

Telephone: 07515151901

Who do I contact with any concerns about this study?

If you have any concerns or complaints about this study or the conduct of individuals conducting this study, then please contact Professor Chris Burton, Head of School, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF or e-mail c.burton@bangor.ac.uk (Telephone: 01248-382556).

Appendix 4: Participant information sheet: Family members/carers

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Discourse and Dementia: An Appreciative Approach

Information about the study

Throughout all our conversations we take positions. These might be positions that reflect our job roles or our place in the family. Verbal positions can quickly change as one person may position themselves as clever but is then positioned as foolish when others belittle them. The ability to reposition ourselves is paramount in the way we show and uphold who we are as a person.

Sometimes, People living with dementia can be positioned as inferior or have their skills and personality ignored by others, even when that person means well. A person living with dementia may find that their attempts to reposition themselves are ignored as others in the conversation place more emphasis on their diagnosis of dementia rather than their individuality.

You are invited to take part in a research study examining whether an Appreciative Inquiry approach can be used by People living with dementia to influence how they are verbally positioned by others.

Current research concerning the verbal positioning of People living with dementia and has tended to dwell on negative experiences. This study aims to explore the positive experiences of People living with dementia which can be used to inform and influence the verbal positioning by others through their experience.

This is a PhD study that is being funded by the local health board.

Why have I been asked to take part?

You have been asked to take part in this study because as a family member or carer of a person living with dementia you have a unique perspective of this person and other People living with dementia.

What does the study involve?

The study will require you to attend a group session which will be no longer than 90 minutes. The group will include other family members or carers of People living with dementia who attend the same social group (e.g. a support group, an art group).

You will watch a film and discuss two case studies as a group and will be asked to feedback your thoughts regarding three questions relating to the case studies.

Throughout the discussions and feedback you will be filmed so that the discussions can be analysed after the session. This video recording will not be shared outside of the research.

Following the research session all the participants will also be invited to an optional dementia awareness session. This is an optional session and not a condition of being involved in the research.

Are there any benefits or risks?

The primary benefits of the research are expected to be long term. The research should add to the knowledge base regarding the positioning of People living with dementia and the use of the Appreciative Inquiry approach.

For all participants their involvement may have a positive impact on the experience of People living with dementia in the future.

In the event that you require personal support following any of the case study discussions, the researcher will support you during this period and will be able to signpost you to other services that can provide continued support.

What will happen to my data?

All data collected will only be accessible to the researcher and all identifiable information will be anonymised. The data from this study will be stored securely for three years. If you choose to withdraw from the study and your data is identifiable to the research team, then you have the right to request that your data is not used.

What if I don't want to take part?

It is up to you to decide whether or not you would like to participate in this study. Your involvement will not affect your rights or access to any available support as a family member of a person living with dementia.

Who do I contact about the study?

Ian Davies-Abbott: Researcher, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF

Telephone: 07515151901

Who do I contact with any concerns about this study?

If you have any concerns or complaints about this study or the conduct of individuals conducting this study, then please contact Professor Chris Burton, Head of School, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF or e-mail c.burton@bangor.ac.uk (Telephone: 01248-382556).

Appendix 5: Participant information sheet: Healthcare workers

School of Healthcare Sciences

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Discourse and Dementia: An Appreciative Approach

Information about the study

Throughout all our conversations we take positions. These might be positions that reflect our job roles or our place in the family. Verbal positions can quickly change as one person may position themselves as clever but is then positioned as foolish when others belittle them. The ability to reposition ourselves is paramount in the way we show and uphold who we are as a person.

Sometimes, People living with dementia can be positioned as inferior or have their skills and personality ignored by others, even when that person means well. A person living with dementia may find that their attempts to reposition themselves are ignored as others in the conversation place more emphasis on their diagnosis of dementia rather than their individuality.

You are invited to take part in a research study examining whether an Appreciative Inquiry approach can be used by People living with dementia to influence how they are verbally positioned by others.

Current research concerning the verbal positioning of People living with dementia and has tended to dwell on negative experiences. This study aims to explore the positive experiences of People living with dementia which can be used to inform and influence the verbal positioning by others through their experience.

This is a PhD study that is being funded by the local health board.

Why have I been asked to take part?

You have been asked to take part in this study because as a healthcare worker you have a unique perspective of People living with dementia.

What does the study involve?

The study will require you to attend a group session which will be no longer than 90 minutes. The group will include other staff members from your nursing home.

You will watch a film and discuss two case studies as a group and will be asked to feedback your thoughts regarding three questions relating to the case studies.

Throughout the discussions and feedback you will be filmed so that the discussions can be analysed after the session. This video recording will not be shared outside of the research.

Following the research session all the participants will also be invited to an optional dementia awareness session. This is an optional session and not a condition of being involved in the research.

Are there any benefits or risks?

The primary benefits of the research are expected to be long term. The research should add to the knowledge base regarding the positioning of People living with dementia and the use of the Appreciative Inquiry approach.

For all participants their involvement may have a positive impact on the experience of People living with dementia in the future.

In the event that you require personal support following any of the case study discussions, the researcher will support you during this period and will be able to signpost you to other services that can provide continued support.

What will happen to my data?

All data collected will only be accessible to the researcher and all identifiable information will be anonymised. The data from this study will be stored securely for three years. If you choose to withdraw from the study and your data is identifiable to the research team, then you have the right to request that your data is not used.

What if I don’t want to take part?

It is up to you to decide whether or not you would like to participate in this study. Deciding not to take part will not impact on any other aspect of your healthcare.

Who do I contact about the study?

Ian Davies-Abbott: Researcher, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF

Telephone: 07515151901

Who do I contact with any concerns about this study?

If you have any concerns or complaints about this study or the conduct of individuals conducting this study, then please contact Professor Chris Burton, Head of School, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF or e-mail c.burton@bangor.ac.uk (Telephone: 01248-382556).

Appendix 6: Participant information sheet: Lay people

School of Healthcare Sciences

Discourse and Dementia: An Appreciative Approach

Information about the study

Throughout all our conversations we take positions. These might be positions that reflect our job roles or our place in the family. Verbal positions can quickly change as one person may position themselves as clever but is then positioned as foolish when others belittle them. The ability to reposition ourselves is paramount in the way we show and uphold who we are as a person.

Sometimes, People living with dementia can be positioned as inferior or have their skills and personality ignored by others, even when that person means well. A person living with dementia may find that their attempts to reposition themselves are ignored as others in the conversation place more emphasis on their diagnosis of dementia rather than their individuality.

You are invited to take part in a research study examining whether an Appreciative Inquiry approach can be used by People living with dementia to influence how they are verbally positioned by others.

Current research concerning the verbal positioning of People living with dementia and has tended to dwell on negative experiences. This study aims to explore the positive experiences of People living with dementia which can be used to inform and influence the verbal positioning by others through their experience.

This is a PhD study that is being funded by the local health board.

Why have I been asked to take part?

You have been asked to take part in this study because as a person with no current caring relationship with a person living with dementia you have a unique perspective of People living with dementia.

What does the study involve?

The study will require you to attend a group session which will be no longer than 90 minutes. The group will include other staff members from your nursing home.

You will watch a film and discuss two case studies as a group and will be asked to feedback your thoughts regarding three questions relating to the case studies.

Throughout the discussions and feedback you will be filmed so that the discussions can be analysed after the session. This video recording will not be shared outside of the research.

Following the research session all the participants will also be invited to an optional dementia awareness session. This is an optional session and not a condition of being involved in the research.

Are there any benefits or risks?

The primary benefits of the research are expected to be long term. The research should add to the knowledge base regarding the positioning of People living with dementia and the use of the Appreciative Inquiry approach.

For all participants their involvement may have a positive impact on the experience of People living with dementia in the future.

In the event that you require personal support following any of the case study discussions, the researcher will support you during this period and will be able to signpost you to other services that can provide continued support.

What will happen to my data?

All data collected will only be accessible to the researcher and all identifiable information will be anonymised. The data from this study will be stored securely for three years. If you choose to withdraw from the study and your data is identifiable to the research team, then you have the right to request that your data is not used.

What if I don't want to take part?

It is up to you to decide whether or not you would like to participate in this study. Deciding not to take part will not impact on any other aspect of your healthcare.

Who do I contact about the study?

Ian Davies-Abbott: Researcher, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF

Telephone: 07515151901

Who do I contact with any concerns about this study?

If you have any concerns or complaints about this study or the conduct of individuals conducting this study, then please contact Professor Chris Burton, Head of School, School of Healthcare Sciences, Bangor University, Bangor Gwynedd LL57 2EF or e-mail c.burton@bangor.ac.uk (Telephone: 01248-382556).

Appendix 7: Scoping review search details

Search One

The search results and the process for inclusion or exclusion of literature is displayed in Table A7 (1)

Table A7 (1)

Search Dates: January 10th to January 28th 2016	
Database	Search terms
	Number of results
Ovid Online	Dementia Position*
Results	74
Titles accepted	74
Duplicates	20
Abstracts screened	54
Rejected	41
Full Text screened	13
Rejected	5
Total entries in scoping review	8

From this search a total of 74 papers were identified. All titles were screened although 20 of the papers were removed as duplicates. A total of 54 papers were screened by abstract and 41 of these papers were rejected. The remaining 13 papers were read as full texts with 5 rejected due to having no documented original verbal positioning. The remaining texts were included in the scoping review.

The paucity of total results was concerning but also justified the use of the scoping review mechanism. Previous authors have justified their own use of the scoping review framework due to the small amount of research available in their area of interest (Guruge & Butt, 2015).

Search Two

A secondary search was conducted using the words and themes that had been apparent from the full texts identified in the original search. This centrifugal development was necessary to capture the data rather than remaining in the central confines of positioning theory. Daudt, Van Mossel and Scott (2013), reacting to the limited amount of research, used a similar process including any mention of information needs regarding colorectal cancer in their search strategy for a scoping review specifically about the information needs of the people with colorectal cancer themselves. The iterative process enhances a scoping review (Levac et al., 2010) and increases the breadth of data captured.

The results are displayed in Table A7 (2)

Table A7 (2)

	Search dates: February 1st to February 10th 2016		
Search terms	Database and number of results		
	Ovid Online	JSTOR	Total new entries in scoping review
(Dementia Discourse) AND la:(eng OR en)	24	86	4
(Dementia Language) AND la:(eng OR en)	191	855	4
(Dementia Stigma) AND la:(eng OR en)	54	845	1
(Dementia Prejudice) AND la:(eng OR en)	1	1066*	0
(Dementia Attitude) AND la:(eng OR en)	110	3275*	0
(Dementia Personhood) AND la:(eng OR en)	32	345	0
((Dementia) AND (Position)) AND la:(eng OR en)	42	400	2

((Dementia) AND (Discourse)) AND la:(eng OR en)	44	86	1
((Dementia) AND (Language)) AND la:(eng OR en)	258	5833*	0
((Dementia) AND (Attitude*)) AND la:(eng OR en)	140	3275*	1
((Dementia) AND (Prejudice)) AND la:(eng OR en)	6	1066*	0
((Dementia) AND (Personhood)) AND la:(eng OR en)	71	345	0
((Dementia) AND (Stigma)) AND la:(eng OR en)	54	230	0

From this search a total of 18, 734 papers were identified. Search terms that had produced more than 1000(*) results were recognised as too large for the reviewer to successfully screen in their entirety. A decision was made to introduce a third search to identify abstracts only with the same search terms. As a mechanism to ensure that no relevant papers were missed the first 200 papers identified in searches with over 1000 results were screened and each subsequent 50 papers were screened until no relevant results were found. The results in JSTOR for search terms 'AND Discourse, AND Attitude*, AND Prejudice and AND Personhood' were discounted due to being duplicates of the previous searches containing the identical suffix. Therefore, the actual amount of papers identified and screened in this search totalled 4,388.

Following the initial screening of titles and the removal of duplicates a total of 513 papers were screened by abstract of which 433 were rejected. The remaining 80 papers were screened as full texts and from these 62 were rejected.

Search Three

To mitigate the risk of papers being missed due to the limitations of the previous search, an abstract only search was completed using the search terms with over 1000 results from search two, displayed in Table A7 (3)

Table A7 (3)

	Search dates: February 1st to February 8th 2016	
Search terms	Database and number of results	
	JSTOR (Abstract)	Total new entries in scoping review
(Dementia Prejudice) AND la:(eng OR en)	0	0
(Dementia Attitude) AND la:(eng OR en)	1	0
((Dementia) AND (Language)) AND la:(eng OR en)	5	0
((Dementia) AND (Attitude*)) AND la:(eng OR en)	2	0
((Dementia) AND (Prejudice)) AND la:(eng OR en)	0	0

The search identified 8 papers which were screened by abstract and rejected due to having no relevance to the scoping review question.

Search Four

The fourth search was completed using Google Scholar. Under the strict controls of a systematic review the use of a search engine such as Google Scholar becomes problematic in comparison to identifying literature from an accepted healthcare database. However, as the quality of the literature is not under scrutiny during a scoping review the same concerns do not apply. A search for *dementia position** in Google Scholar produced ‘about 940,000 results’. This was an unmanageable amount of results and therefore the decision was made to review the first 1000 results. The suggestions made by Levac, Colquhoun and O'Brien (2010) include the understanding that the scope of the inquiry may have to be limited but under those circumstances there must be a justification. The decision to limit the amount of results reviewed was initially justified by the need to complete the scoping review in a timely manner (which would have been adversely affected). The decision was justified again during the review as the results that were accepted into the scoping review were identified during the first 500 results. These results are shown in Table A7 (4)

Table A7 (4)

Search dates: February 10th to March 28th 2016		
Search terms	Database and number of results	
	Google Scholar	Total new entries in scoping review
Dementia and Position*	1000	21

From the 1000 papers identified a total of 131 were screened at abstract of which 53 were rejected. The remaining 78 papers were read as full texts with 56 rejected from the review. The total of 22 new entries justified the use of the Google scholar search engine. Although these papers were identified in subsequent searches, as duplicates, including the papers at this stage was integral to informing the search terms for search five.

Due to the unwieldy number of results in a Google Scholar search, no further searches were attempted in this search engine. However, the results of this and previous searches were used to inform the next phase of searches.

Search Five

From the papers that had been accepted from the previous searches, recurring themes were identified to inform the next group of search terms – see Table A7 (5).

Table A7 (5)

Search dates: April 21st to August 19th 2016							
Search terms	Database and number of results						
	Ovid Online	ASSIA	CINAHL complete	PubMed	PsycINFO	JSTOR	Total new entries in scoping review
((Dementia) AND (Position*)) AND la:(eng OR en)		72	233	2002*	624	400	12
((Dementia) AND (Identity)) AND la:(eng OR en)	79	74	31	708	723	418	6
((Dementia) AND (Self)) AND la:(eng OR en)	275	438	183	6637*	4801*	2377*	5
((Dementia) AND (Malignant)) AND la:(eng OR en)	25	9	1	463	169	989*	0
((Dementia) AND (Social Construction)) AND la:(eng OR en)	2	27	32	103	244	320	0

((Dementia) AND (Conversation*)) AND la:(eng OR en)	27	50	32	206	388	320	2
((Dementia) AND (Narrative)) AND la:(eng OR en)	77	74	32	633	554	124	4
((Nursing) AND (Position*)) AND la:(eng OR en)	90	8	0	11,784*	2907*	990*	0

From this search an initial total of 41, 780 papers were identified. The same process, used in search two, was used to limit the number of papers (*) screened with an abstract search in search six. A total of 8,488 papers were identified with 7,238 rejected at title due to lack of relevance or duplication. A total of 1,250 papers were screened by abstract with 1,045 rejected leaving 205 papers that were scrutinised through the full texts. A total of 176 papers were rejected with the remaining papers included in the scoping review.

Search Six

To ensure that no relevant papers were missed the same process was followed as documented in search three – see Table A7 (6).

Table A7 (6)

Search dates: August 22nd to September 24th 2016				
Search terms	Database and number of results			
	PubMed (Title)	PsycINFO (Keyword)	JSTOR (Abstract)	Total new entries in scoping review
((Dementia) AND (Position*)) AND la:(eng OR en)	35			0
((Dementia) AND (Self)) AND la:(eng OR en)	256	1302*	14	0
((Dementia) AND (Malignant)) AND la:(eng OR en)			1	0
((Nursing) AND (Position*)) AND la:(eng OR en)	457*	48	0	0

A total of 2,113 papers were identified. However, no new papers were identified that required screening at abstract. The papers relating to AND Self and Nursing AND Position* were screened for the first 200 results of each larger search result (*). The decision to end the screening of papers at this point was due to the amount of duplicates when compared with previous searches and the lack of viable results. In total 754 papers were screened at title.

Search Seven

A total of 71 papers including the verbal positioning of people living with dementia were identified. The reference lists from these papers were then used to inform a hand search of papers that had not been identified during the process. The papers identified were gathered online or, if necessary, a physical copy was requested from the health board library service. From the reference lists a total of 23 papers were identified. A total of 18 papers were screened by abstract online and rejected. A total of 5 papers were physically requested of which 4 were rejected at abstract. A total of 1 paper was screened as a full text and was rejected.

Appendix 8: Tables of literature included in the scoping review

The papers selected for inclusion are presented in the following tables. Each paper has been given a numerical identifier. Several papers provided data under more than one theme and are included in subsequent tables from their original inclusion.

Scoping review: How do people living with dementia verbally position themselves?

Positioning theory focussed.

Data Collection	Date	Contribution	Author(s)	Number
Interviews Observation Informal conversation Thematic Analysis	2013	In the immediate term, people with severe dementia retain an ability to influence the relational patterns during conversation. Potentially people with severe dementia could intentionally reposition themselves within a care triad.	Bourbonnais and Ducharme	#1
Book chapter Observation	2013	Care staff may exert power over people living with dementia through use of prepositioning and malignant social psychology. This may result in the person living with dementia becoming lonely, passive and restrict their identity to 'dementia patient'.	de Medeiros and Sabat	#2
Interviews Conversational analysis	2015	The pronoun 'we' is used less by the partner with dementia in couples. The concept of 'we-ness' suggests that couples share identities through couplehood and their identities share mutual dependence.	Hyden and Nilsson	#3
Recorded meetings Interactional analysis	2015	People living with dementia are often orally positioned as lacking competence and therefore suffer more discrimination than other older people. People living with dementia often attempt to reposition themselves as competent.	ÖSterholm and Samuelsson	#4
Interview Conversational analysis Thematic analysis	2010	Family members position each other in a constantly changing manner due to the 'diversity of selves'. People living with dementia should be	Purves	#5

Constant comparative analysis		viewed as a person not a person living with dementia. Formal caregivers risk stereotyping the person living with dementia as they only know them in terms of the social construction of dementia.		
Book chapter Interview	2007	What people living with dementia say and do is not a reflection of pathological symptoms but due to incorrect assumptions made by others regarding dysfunctional attributes.	Sabat	#6
Interviews Social constructionism	1992	The personal identity 'self' persists in the latter stages of dementia. The public arena 'self' can be lost but as a result of how others view and treat the person living with dementia more than as a direct result of dementia.	Sabat and Harre	#7
Case study Interviews Observation	2004	A degree of neuropathology dysfunction can lead to malignant positioning. Malignant positioning is a springboard for malignant social psychology. A person living with dementia who attempts to reposition themselves should not be viewed as dysfunctional but as expressing pride, self-respect with the possibility of creating a valued social identity.	Sabat, Napolitano and Fath	#8

Scoping review: How do people living with dementia view the verbal positioning of people living with dementia by others?				
Positioning theory focussed.				
Data Collection	Date	Contribution	Author(s)	Number
	2013		de Medeiros and Sabat	#2

Scoping review: How are people living with dementia verbally positioned by others?				
Positioning theory focussed.				
Data Collection	Date	Contribution	Author(s)	Number
	2013		Bourbonnais and Ducharme	#1
	2013		de Medeiros and Sabat	#2
Observation Focussed coding	2005	Both person living with dementia and spouse are subjectified and objectified during group conversations as a means of 'survival' in coping with a spouse with dementia. People living with dementia are often referred to by spouses in objectifying terms who acknowledge the subjective self of the person living with dementia at the same time.	Golden and Lund	#9
	2015		Hyden and Nilsson	#3
Qualitative interview	2015	Family caregivers and health professional's participation in people living with dementia's care is enhanced or threatened by the constant	Larsen, Normann and Hamran	#10

		movement in the positions of participants. Collaboration is improved when formal and family caregivers position the person living with dementia as a ‘confused patient’ in need of care.		
	2015		Österholm and Samuelsson	#4
	2010		Purves	#5
	2007		Sabat	#6
Book chapter	2005	Meaning drives the actions of people living with dementia but when carers do not account for meaning, malignant positioning begins.	Sabat	#11
Book chapter	2000	There is little people living with dementia can do to reject a negative position. Caregivers must recognise malignant positioning in their own thoughts and actions before they can reduce the effects of malignant positioning on the person living with dementia.	Sabat	#12
	1992		Sabat and Harre	#7
Case studies from previous research Discourse analysis Social construction theory	2005	Diagnosis and memory problems may result in negative positioning, obscuring the person living with dementia’s abilities to make decisions and therefore create the possibility of inflicting lasting harm on the person living with dementia.	Sabat	#13
	2004		Sabat, Napolitano and Fath	#8

Scoping review: How do people living with dementia verbally position themselves?

Positioning theory acknowledged.

Data Collection	Date	Contribution	Author(s)	Number
Interviews Social construction Conversation analysis Discursive analysis	2003	Health professionals can help carers positively reposition the person living with dementia by focussing on the narratives of the care dyad (person living with dementia and carer) considering the construction the past which accounts for current difficulties.	Forbat	#14
Semi-structured interviews Qualitative content analysis	2013	People living with dementia displayed an awareness that malignant positioning could occur due to the ignorance of others and that they personally may also have engaged in the malignant positioning of people living with dementia prior to their diagnosis. People living with dementia did not see AD as something to be ashamed of.	Hedman *et al.*	#15
Interview Interpretative Phenomenological Analysis	2007	People living with dementia do not like the terms dementia or AD and do not want to share their diagnosis with those outside their private social circle. People living with dementia want to carry on life as normally as possible following diagnosis.	Langdon, Eagle and Warner	#16
Observations Discourse analysis Discourse positioning	1998	When the person living with dementia was positioned as incompetent they resisted formal care. When positioned as independent they co-operated, suggesting that the preferable position for people living with dementia is independent.	Small, Geldart and Gutman	#17

Book chapter	2005	Our own fictions must be acknowledged I we are to honour the enduring self of people living with dementia. people living with dementia must be positioned as teachers and listened to.	Snyder	#18
Book chapter Storylines Critical reflection	2010	There are no universal narratives. Language used by others creates or disables the social citizenship of people living with dementia	Bartlett and O'Connor	#19

Scoping review: Scoping review: How do people living with dementia view the verbal positioning of people living with dementia by others?

Positioning theory acknowledged.

Data Collection	Date	Contribution	Author(s)	Number
	2013		Hedman *et al.*	#15
	2007		Langdon, Eagle and Warner	#16
	2005		Snyder	#18

Scoping review: How are people living with dementia verbally positioned by others?

Positioning theory acknowledged.

Data Collection/Analysis	Date	Contribution	Author(s)	Number
Observation Conversational analysis Social construction Inferential communication	2005	Constantly changing positions in dementia care triads are unavoidable due to constantly changing members. Presents two types of communication: 'enabling' and 'disabling'. Suggests that health care providers can empower people living with dementia in the face of 'disabling' carer communication.	Adams and Gardiner	#20
Practice examples Social construction Inferential communication	2007	What each member says in a dementia care triad can result in an unequal balance of power resulting in members being excluded from the decision making process.	Adams *et al.*	#21
Observation Engaging with people living with dementia Dementia Care Mapping Kitwoods (1997) personhood	2010b	Healthcare staff's interactions with people living with dementia were often limited and sometimes abusive. Suggests that the old culture of institutional and regimental care still exists.	Kelly	#22
Observation Engaging with people living with dementia Dementia Care Mapping	2010a	Indicates abusive practices occurring in wards and although people living with dementia offer self-defence and resistance they are ultimately defeated. Whilst selfhood endures it is often neither recognised or supported by healthcare staff.	Kelly	#23
	2007		Langdon, Eagle and Warner	#16

Case studies from previous research	2006	Unpleasant or distressing events may be viewed as having no 'lasting harm' due to the person living with dementia's memory difficulties. Without an understanding of implicit memory, caregivers are likely to engage in malignant positioning.	Sabat	#24
	1998		Small, Geldart and Gutman	#17
	2010		Bartlett and O'Connor	#19
	2003		Forbat	#14

Scoping review: How do people living with dementia verbally position themselves?

Positioning theory absent.

Data Collection	Date	Contribution	Author(s)	Number
Spontaneously produced narrative Narrative Analysis	2014	Narratives concerning life-long disability allow areas of resilience for the person living with dementia. An enduring sense of self is linked by self, society and body illness.	Angus and Bowen-Osborne	#25
Ethnography Naturalistic Inquiry	2013	Maintenance of an equal partnership with people living with dementia is directly influenced by the setting of care, health workers and our perceptions of the diagnosis and symptoms.	Arieli	#26
Semi-structured interviews Thematic categories Conceptual classification	2015	Expressions of self are limited in people living with dementia when spoken to as a person living with dementia. People living with dementia displayed an understanding of roles and relationships.	Batra, Williams and Geldmacher	#27
Semi-structured and open ended interviews Focus groups Grounded Theory Phenomenology	2004	Active people living with dementia want to be spokespeople for dementia services but are aware that society does not always recognise their voices.	Beard	#28
Interview Interpretative Phenomenological Analysis	2011	The majority of people living with dementia expressed a belief they would ‘remain the same or less vocal about being concerned about alterations caused by progressive dementia. The inability to complete identity activities that rely on lost skills results in a decreased projection of identity in people living with dementia.	Caddell and Clare	#29

Taped conversation Conversational analysis Discourse analysis	2004	Conversational features that undermine the social presentation and identity of the person living with dementia are present even at the early stages of dementia. A process of family carers developing malignant social psychology may be contained within conversation.	Clare and Shakespeare	#30
In depth interviews Reflection Interpretative Phenomenological Analysis	2003	The minimisation of difficulties by people living with dementia is an approach to maintain the prior sense of self not a reflection of a symptom. Partners of people living with dementia have a better understanding of the meaning behind people living with dementia's language.	Clare	#31
Interviews Research diaries Constant thematic comparative analysis	2016	Narrative citizenship may be supported by familiarity of people and places through stories of inclusion and feeling 'on the inside'. For others, the same familiarity can create social barriers caused by feelings of estrangement and being 'on the outside'.	Clarke and Bailey	#32
Semi-structured interviews Questionnaires Narrative analysis Thematic analysis	2011	Changes in the 'us identity' occurred in couples when one partner has dementia but remained present. Couples in the early stages of dementia were as satisfied with their lives as the general population.	Davies	#33
Semi-structured interviews Interpretative Phenomenological Analysis Hermeneutic scrutiny	2015	Signs of individuality remain in the late stages of dementia. Carers may have a different perspective on the person living with dementia's sense of self but did feel that personality was preserved to some degree.	Godwin and Poland	#34

Interview Interpretative Phenomenological Analysis	2012	For female people living with dementia tension exists between the remaining desire to exhibit an authentic social presentation of selfhood and the concern that they may be seen as a 'silly old woman'.	Frazer, Oyebode and Cleary	#35
Ethnographic observation Social construction Symbolic interactionist perspective	1996	The use of indexicals ('I', 'me') in people living with dementia does not suggest a retention of pre-self but could be included in speech lacking content. Indexicals are only meaningful if their intention is known which is problematic in people living with dementia.	Golander and Raz	#36
Semi-structured interviews Self-regulation model	2006	A tensions exists between acknowledging the implications of dementia and keeping the sense of being 'the same person'. For some people living with dementia there is an acute sense of stigmatisation, exclusion and possibly betrayal.	Harman and Clare	#37
Interviews Thematic questions Secondary analysis of data from previous research Cognitive semantic theory	2014	Metaphorical categories of the lived experience of everyday life for people with young onset dementia included 'sliding away', 'leaving traces' and 'all alone in the world'.	Johannessen *et al.*	#38
Book chapter Observations and interaction	2001	Interpretation of speech by people living with dementia is subjective but individually distinctive.	Killick and Allan	#39
Doctoral thesis Interviews from four studies Case study Phenomenological hermeneutics	2013	Being an adult child of a person living with dementia means being burdened and having a vivid sense of grief of loss. People living with dementia who engaged in a support group felt that life was manageable and meaningful.	Kjällman-Alm, Norbergh and Hellzen	#40

Content analysis				
Qualitative interview Coding	2008	Stigma occurs due to chronic mental illness and negative stereotypes of ageing. These negative stereotypes have a greater negative impact on the person living with dementia compared to the family caregiver.	Liu *et al.*	#41
Semi-structured interviews Phenomenology Symbolic interactionist perspective	2010	Positive responses of others enable People living with dementia to construct and maintain identity. People living with dementia's sense of self is based on current roles but also those roles no longer played.	MacRae	#42
Interviews Interpretative Phenomenological Analysis	2016	The adjustment to a dementia diagnosis results in loss and reconstruction oriented positions being taken. Services taking loss oriented positions risk engaging in malignant social psychology.	Merrick, Camic and O'Shaughnessy	#43
Interview Interpretative Phenomenological Analysis	2013	Healthcare worker's respect for individual personhood was not always received or expected by people living with dementia. People living with dementia do not want to place themselves with those in a different stage of the illness: the 'strange' others.	Nowell, Thornton and Simpson	#44
Interactions between people living with dementia Template analysis	2006	People living with dementia attempt to position themselves within a support group to make connections, find allies and receive support. People living with dementia emphasised their role and contribution within the caregiver relationship.	Offord *et al.*	#45
Interviews Observation	2014	Conflict exists between living well with dementia and surviving the negative attitudes towards	O'Sullivan, Hocking and Spence	#46

Critical hermeneutics		People living with dementia in social discourse. People living with dementia construct their everyday lives against a background of prejudice.		
Interviews Observation Interpretative Phenomenological Analysis	2013	Adult children view the person living with dementia's inability to complete usual activities as a signal of fundamental change in identity. Changes in gender specific roles caused by deteriorating abilities results in family life being disrupted and changes in relational patterns.	Phinney, Dahlke and Purves	#47
Semi-structured interviews Interpretative Phenomenological Analysis	2007	People living with dementia reviewed and adjusted to the negative appraisals of their difficulties by considering the wider context ('putting things into perspective') or accepting their difficulties so that they appeared less threatening.	Preston, Marshall and Bucks	#48
Semi-structured interviews Longitudinal narrative design Narrative analysis	2014	Family functioning affects the experience of living with dementia. Families may be in danger of losing their overall sense of self due to young onset dementia.	Roach *et al.*	#49
Biographical narrative interviews Narrative analysis	2014	Narratives of carers describe People living with dementia as either ordinary people whose abilities are altered by cognitive impairment or as someone whose self and social identity have been irrevocably changed by dementia.	Robertson	#50
Case study Unstructured interviews Structural analysis Narrative analysis	2013	A description by people living with dementia of being socially 'up there' to 'down here' represents the struggle to sustain a sense of worth despite a marginalised social position.	Robertson	#51

Joint interview Interpretative Phenomenological Analysis Thematic analysis	2005	Spouses may position themselves in conversation with people living with dementia to achieve goals and present problems so that they do not risk upsetting their partner. University educated couples tended to understand dementia similar to health professionals.	Robinson, Clare and Evans	#52
Ethnographic observations Discourse analysis	2011	People living with dementia align their social identities (old v. young self) when conversing with each other. This may lead to misunderstandings but relationships persevere similar to those experienced by non-diagnosed people.	Saunders *et al.*	#53
Conversation between couples Conversational analysis	2005	Partners without dementia tend to establish more interactional rights during conversation than the person living with dementia.	Shakespeare and Clare	#54
Interview Grounded Theory Data and analysis triangulation	2007	Central to the experience of the person living with dementia is being valued, rather than the loss of cognition or identity.	Steeman *et al.*	#55
Unstructured interviews Thematic textural analysis	2006	A significant preservation of self is related to the adaptation of social roles relating to being a part of a family, work, caring for and being cared for. How families, healthcare staff and others perceive these roles is also significant.	Surr	#56
Interviews Qualitative cross sectional study	2014	Loss of dignity is reported when people living with dementia are positioned as patients suffering from dementia but upheld when they are regarded as complete individuals.	Van Gennip *et al.*	#57

Scoping review: Scoping review: How do people living with dementia view the verbal positioning of people living with dementia by others?

Positioning theory absent.

Data Collection	Date	Contribution	Author(s)	Number
	2003		Clare	#31
	2016		Clarke and Bailey	#32
	2012		Frazer, Oyebode and Cleary	#35
Observation Reflective dialogue Thematic analysis	2001	Dialogue between people living with dementia and health professionals concerns autonomy, identity, security and privacy which are intertwined but in conflict with one another.	Graneheim, Norberg and Jansson	#58
	2006		Harman and Clare	#37
	2014		Johannessen *et al.*	#38
	2016		Merrick, Camic and O’Shaughnessy	#43
	2014		O’Sullivan, Hocking and Spence	#46
Interviews Thematic analysis	2016	The grief that spouse’s feel following the diagnosis of their partner’s dementia may ease the grieving process following death.	Peacock, Gibson, Holtslander, Thompson and O’Connell	#59
Open ended interviews Thorne’s (1994) secondary analysis	2002	Wives caring for husbands with dementia tend to prioritise protecting them from recognising their deteriorating abilities. Husbands caring for wives with dementia tend to prioritise presenting others with a façade of normality.	Perry and O’Connor	#60

	2007		Preston, Marshall and Bucks	#48
	2013		Robertson	#51
Semi-structured interviews Focus groups Grounded Theory Sequential and comparative analysis	2007	People living with dementia's lives do not lose meaning as their attempts to deal with the disease, engage with others and develop coping strategies continue. When personhood is respected, dignity can be experienced at the person living with dementia's end of life.	Roger	#61
	2007		Steeman *et al.*	#55
	2006		Surr	#56
	2014		Van Gennip *et al.*	#57

Scoping review: How are people living with dementia verbally positioned by others?

Positioning theory absent.

Data Collection	Date	Contribution	Author(s)	Number
	2013		Arieli	#26
	2004	.	Clare and Shakespeare	#30
	2003		Clare	#31
	2016		Clarke and Bailey	#32
	2011		Davies	#33
	2015		Godwin and Poland	#34
	1996		Golander and Raz	#36
	2001		Graneheim, Norberg and Jansson	#58
	2001		Killick and Allan	#39
Narrative interviews Phenomenological hermeneutics Structural analysis	2013	Adult children require support to adapt to the fact they have ‘lost’ a parent who is still alive.	Kjällman-Alm, Norbergh and Hellzen	#62
Case study Thematic analysis	2014	Family members have to adapt to changes in the person living with dementia whilst retaining their role as ‘husband/father’. Communication is	Kindell *et al.*	#63

		primarily about emotional connections and relationships.		
	2014		Kjällman-Alm, Norbergh and Hellzen	#40
	2008		Liu *et al.*	#41
	2016		Merrick, Camic and O'Shaughnessy	#43
Semi-structured interviews Interpretative Phenomenological Analysis	2010	Spouse caregivers experience a continual process of repositioning themselves in relation to their partner with dementia and their couplehood. A strong attachment remains although a sense of separation is experienced between the person living with dementia and their spouse.	O'Shaughnessy, Lee and Lintern	#64
	2014		O'Sullivan, Hocking and Spence	#46
	2016		Peacock, Gibson, Holtslander, Thompson and O'Connell	#59
	2002		Perry and O'Connor	#60
	2013		Phinney, Dahlke and Purves	#47
Ward observation	2016	Medical students have limited outlets for emotional ventilation resulting in untapped grief due to continued exposure to the infirm. This results in malignant positioning, resulting in malignant social psychology.	Resnick	#65
Sem	2014		Roach *et al.*	#49

	2014		Robertson	#50
	2013		Robertson	#51
	2005		Robinson, Clare and Evans	#52
	2007		Roger	#61
Narrative interviews Phenomenological hermeneutical interpretation	2013	The ability to care for each other is retained in the severe stages of dementia. By being open and receptive to another is implicitly tied to being a human being.	Sellevold *et al.*	#66
	2005		Shakespeare and Clare	#54
Interviews Domestic talk Conversation analysis	2004	Choice of identity is frequently unavailable to confused speakers. Confusion may be regarded a permanent part of identity in some speakers.	Shakespeare	#67
Interviews Thematic analysis	2016	Young people deny the 'still the same' person narrative when a parent has dementia. They do not want to believe that their parent in 'their right mind' would speak and act the way they are doing. There is a difference between how younger people experience dementia and their expectations of the person living with dementia when the person is younger or older.	Sikes and Hall	#68
Conversations Qualitative and structured analysis Coding	2016	There are few opportunities for people living with dementia to communicate their intellectual and social needs which are often ignored by nurses who focus on the person's physical needs.	Söderlund *et al.*	#69

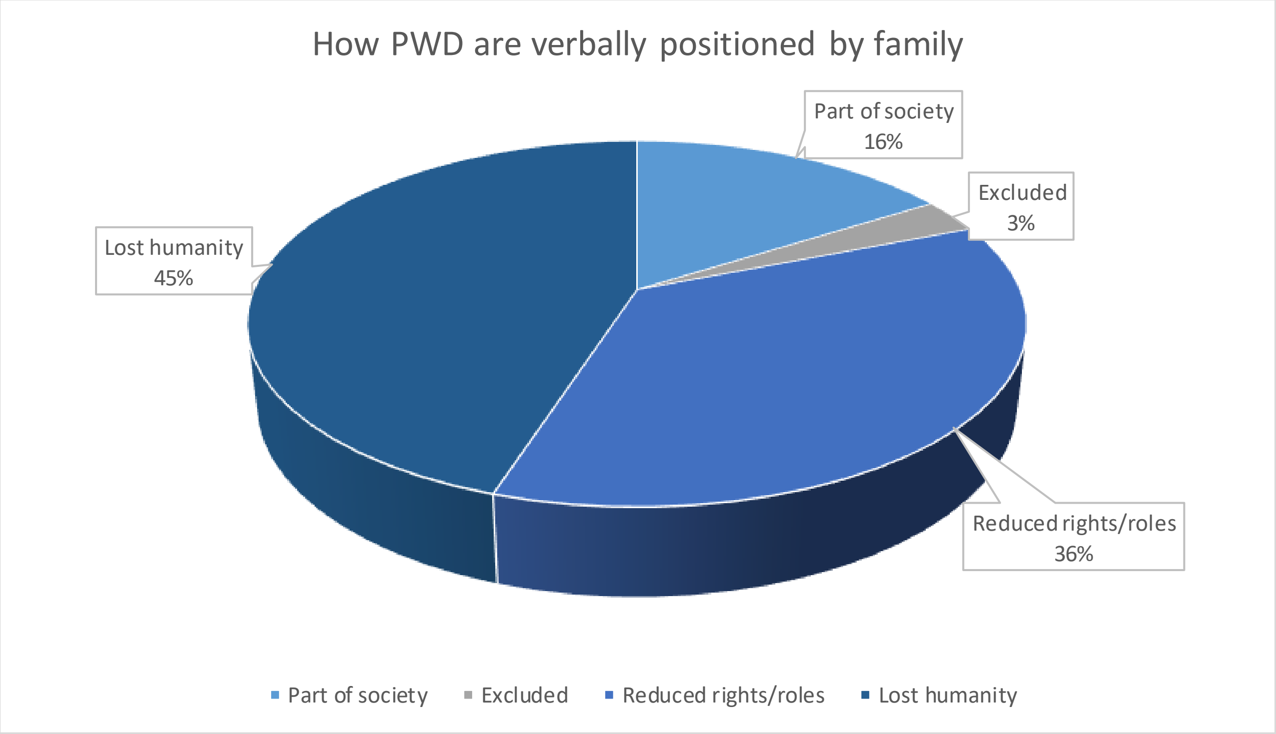
	2007		Steeman *et al.*	#55
One to one interviews Focus groups Grounded theory	2006	People living with dementia are positioned as being on the outside by older people without dementia who view them as 'others'. Older people who would fear going into long term care feel it is appropriate for people with a cognitive impairment.	Townsend, Godfrey and Denby	#70
	2010	Spouse's negative emotions are 'legitimized' by holding a negative perception of the person living with dementia. Thoughts of 'he can't really help it', remove the legitimacy of these thoughts which are replaced by guilt.	Walters, Oyebode and Riley	#71

Appendix 9: Synthesis of individual domain results

Societal standing analysis

The coding of positions within the existing literature supported an overall theme of *societal standing* which was relevant to all groups. Nevertheless, positions regarding being *part of society* and being *excluded* were predominantly created by people living with dementia themselves. In comparison, a position of *reduced rights* was not observed within the positioning by people living with dementia (see Chart 2) but was a regular position within both family and healthcare worker groups (see Chart A9 (1) and Chart 4).

Chart A9 (1)



The acknowledgement of the *reduced rights* position is observed in the recent developments of 'Our Dementia, Our Rights' by the Dementia Engagement & Empowerment Project (Hare, 2016) and the statement from the Alzheimer's Disease International (Splaine, 2016). The former document cites paternalistic attitudes and services as the cause of stigma towards people living with dementia which in turn creates discrimination and a reduction in rights. The result of this discrimination is that people living with dementia lose out on support as they become a passenger within their own lives. The document reflects the findings of the scoping review which displays that people living with dementia are aware of this positioning by others regarding *reduced rights* but do not contribute to this position as a group. However, the inferior occurrence of positioning by others regarding *part of society* and the high occurrence of *lost humanity* does not suggest a position for people living with dementia as a passive group but rather adds to the evidence that this group is *excluded.*

Splaine's (2016) statement on behalf of Alzheimer’s Disease International (ADI) proposes action to address the social exclusion of people living with dementia and ties this to both stigma and a violation of human rights. The proposal suggests a resolution supported by the ADI’s eighty-five national member organisations to adopt a policy strategy to realise the human rights of all people living with dementia. Although the scoping review results also acknowledge the threat to human rights by *reduced rights* positions, the most clear example being rape causing ‘no lasting harm (Sabat, 2007), the *reduced rights* position in the literature also implies the loss of other rights. The sub-theme *worthy of derision* acknowledges that the visibility of behaviours possibly caused by the physiological changes of dementia may be used by others to belittle or mock the people living with dementia (Adams & Gardiner, 2005; Liu et al., 2008). This creates the further position, observed in healthcare worker positional examples, of the person living with dementia being acceptably intimidated and imposed upon (Kelly, 2010b). These examples illustrate the loss of rights regarding the person living with dementia’s ability to display the symptoms of dementia without becoming *worthy of derision.*

The theme of *social standing* allows thematic comparisons to theories of social class and power. The genesis of Marx’s (1818-1883) social class theory may have its roots in his observations of social exclusion and struggle but the theory’s focus is predominantly economical. Marx identified production as the means to bifurcate the privileged capitalist class from the working class (Jordan, 1971). Ownership of production grants an economic base for power that supports the owner’s social, political and cultural interests. Weber (1864-1924) (Gerth et al., 2013) agreed that class was influenced by economic power, including wealth in his three-component theory of stratification, but added the two non-economic areas of prestige and power as influencers of status. Power is exercised by domination which requires authority. Weber identified three existing forms of authority.

- Charismatic authority

  This form of power is dependent on a person's character. Often people find or place themselves in positions of charismatic authority through their communication and leadership skills. Charismatic authority is not dependent on an official position but may be borne out of culture. Within healthcare, a healthcare assistant who has worked on the same ward for thirty years may be viewed as having charismatic authority due to their experience, even if this power is not necessarily viewed positively by other areas of authority. Due to its informal position charismatic authority will not be constantly held by one person but tends to become apparent during periods of crisis when a leader, not directly tied to formal authority, is desired by others.
- Traditional authority

  In this domain power is based upon social norms. Therefore, if one is placed in a position that is considered to have an inherent authority within its title, traditional authority is granted. This power may be formally more acceptable than charismatic authority but will still be finite within its time frame. Within healthcare, a ward manager has inherently more power than a healthcare assistant but loses that power with the loss of their title.
- Rational-legal authority

  This is the most consistent form of power, based upon established rules and upheld through bureaucracy. Rational-legal authority does not tend to be held by a person as the power resides within an office or system. Within healthcare, policies are the created definitions of rational-legal authority that no individual, no matter their position, can ignore without contention.

The *social standing* results in the scoping review create an understanding regarding the position of people living with dementia within the literature in relation to Weber's stratification. By acknowledging the person living with dementia as *part of society,* particularly within the *family* sub-theme, the person living with dementia retains any traditional authority that existed prior to their diagnosis. The couple relationship described as 'stable' (Hydén & Nilsson, 2015) and pronouns 'us' and 'we' suggests the continuation of a previous relationship, whether as a spouse or parent, and therefore the person living with dementia maintains the inherent authority within these roles. Being positioned as a 'lover' (Surr, 2006) or, within *friendship*, as an equal partner (Arieli, 2013) supports the potentiality of charismatic authority. The positions relating to being *part of society* are not exclusively, but predominantly, within the positioning by people living with dementia and family members. Such positioning may promote the retention of previous authority and counterbalance the assumed disintegration of personhood in dementia.

The retention of any dimension of authority is removed within the *reduced rights* theme. The speakers within this theme dismiss the person living with dementia's right to authority and, in some cases, position themselves within the tiers of authority. By positioning the person living with dementia as having less interactional rights (Shakespeare & Clare, 2005) or acting like a child (Liu et al., 2008) the speaker places themselves as a holder of traditional authority. The speaker does not recognise the person living with dementia as holding any authority and therefore power belongs exclusively to the speaker. Within the *excluded* subtheme *a victim of others,* the person living with dementia states a desire to argue about being negatively positioned by others (Preston, Marshall & Bucks, 2007) but within the frame of Weberian stratification the person living with dementia has no authority to reposition themselves due to the initial positioning by others. The mockery within the *worthy of derision* subtheme describing the person living with dementia 'fighting off the nurses' and 'lost in the shops and you still had your dressing gown on' (Adams & Gardiner, 2005) not only places the person living with dementia outside the domains of authority but also suggests a position directly opposed to rational-legal authority. Expected social behaviour is used as rational-legal authority in these examples with the person living with dementia positioned by others as no longer able to function in a manner that is acceptable to others and therefore the position is used to further remove the individual's power. For a wife who may have previously held a traditional authority as the leading woman of the household, this positioning strips the individual of her role and authority.

The person living with dementia s absence in Weberian stratification is also observed in both the *excluded* and *lost humanity* themes. The latter theme distances the person living with dementia from issues of authority by questioning humanity itself. Objectification and depersonalisation are examples throughout the positioning by family members and healthcare workers which question humanity rather than authority.

The view of people living with dementia that lay people no longer see people living with dementia as part of society (O'Sullivan et al., 2014) and people living with dementia's own positioning of being outside society (Johannessen, et al., 2014) denies the charismatic and traditional authority that had been supported within the *part of society* theme. The continued distancing of people living with dementia from the stratification model is perpetuated within the *not like us* theme. Within this theme, there are no issues regarding the establishment of people living with dementia's authority as the person living with dementia is now positioned as different to the rest of society or the rest of humanity and therefore no longer compatible with standard social theories.

It is evident that there are significant differences regarding the positioning by people living with dementia when compared to other groups in regards to the theme of *social standing*. The higher occurrence in people living with dementia's positioning relating to *part of society* suggests a continued need to be present in society, preferably in stable social relationships which allow the retention of charismatic or traditional authority. The higher occurrence of *excluded* positioning by people living with dementia, however, suggests that people living with dementia may feel socially isolated and lack authority. This mirrors the positioning by other groups who are more likely to position the person living with dementia in regards to having *reduced rights* and *lost humanity* rather than in a position of continued authority and social value. Although *social standing* is clearly evidenced in the literature as an important theme for people living with dementia, this group is restricted in regards of their ability to reposition themselves due to the positioning of others that places people living with dementia outside the frame of Weberian stratification. This is amplified as the positioning by others places these groups within the frame of traditional authority with an ability to use rational-legal authority to dismiss attempted repositioning by people living with dementia.

Practical ability analysis

The formation of a domain concerning the *practical ability* of people living with dementia may be regarded as an inevitability due to the positioning directly reflecting a necessary symptom of a dementia diagnosis. Positional examples within the themes of *current ability* and *dependent* address the positioner's view of the person living with dementia's practical strengths or weaknesses. Although examples within the *lacking ability* theme also contained several of these views they also encapsulate the examples that were used to negatively position the person living with dementia regarding a perceived lack of practical ability.

The World Health Organisation (Wortmann, 2012) regard a deterioration in a person's practical ability as a common symptom even in the earlier stages of dementia. Frequent issues may concern the person living with dementia struggling to make decisions or execute everyday complex tasks. Although these symptoms are an accepted part of dementia, the reaction of others is not necessarily one of sympathy or understanding. The deterioration in practical ability has been considered a significant contributor in what may be regarded as 'caregiver burden' (Desai, Grossberg, & Sheth, 2004). Therefore, although the domain of *practical ability* can be accepted as inevitable in verbal positioning it is perhaps also inevitable that these positions, when provided by caregivers, will also reflect the sense of burden that they may now feel due to the person living with dementia's failing abilities. It is this burden that appears to inform the majority of positioning examples by others in both the *unwanted* and *a lesser person* subthemes.

The marked difference between how people living with dementia verbally position themselves within the *practical ability* domain in comparison to all other groups is the minimal occurrences of *current ability* positions within the latter group's examples (see Chart 7). Examples from other groups within *a lesser person* include the infantilization of the person living with dementia. People living with dementia may attempt to position themselves positively regarding their abilities but are unlikely to counter a second order position by another group which positions them as childlike. If the person living with dementia is positioned as a child their counter positions are given the same weight as those granted an infant within the same conversation. It is not uncommon to hear a lay person perspective that people living with dementia are similar to children or should be treated like children. This is reflected in the presence of infantilization as one of the seventeen hallmarks of malignant social psychology (Kitwood, 1998). However, the notion of the person living with dementia as childlike has also been formally addressed through academic theory whilst being presented as biological fact. The theoretical process of retrogenesis (Reisberg et al., 2002) has suggested that the decline in practical ability witnessed in a person with Alzheimer's type dementia replicates the functional gains as seen in standard human development. Neuropathological mechanisms are used to support the theory by comparing myelin loss in people living with dementia and myelin gain in children. The human nervous system depends on myelin, a composite of different cells, to function correctly. The theory suggests that the pattern of myelin loss for a person with Alzheimer's type dementia mirrors the acquisition of myelin in typical human development. The theory of retrogenesis appears to perpetuate the position of people living with dementia as childlike. However, it may also be argued that those who position the person living with dementia negatively due to failing abilities may be less inclined to do so if they accept the theory's standpoint that dementia causes a reversal in human development.

Although the process of practically being able to complete a task suggests an equal focus on a person's physical and cognitive strengths, in the examples within the domain there is very little to suggest that this positioning occurs due to physical deterioration. The examples suggest that the focus of positioning is less on what the person living with dementia is able to physically achieve but more representative of what each group considers the person living with dementia is able to intellectually accomplish.

The notion of practical intelligence is addressed as one of the components in the triarchic theory of intelligence (Sternberg, 1985). The theory considers human intelligence as being composed of three aspects (Sternberg, 1988):

- Analytical (componential) intelligence
  This represents possibly the most traditionally accepted form of intelligence. It involves evaluation, judgement, thought and reasoning.
- Creative (experiential) intelligence
  This concerns original ways of thinking when a person is presented with problems or situations that they may not have previously experienced. It may encompass creativity, the need for invention or to make predictions.
- Practical (contextual) intelligence
  This represents how a person applies their knowledge to the real world. It concerns how a person may assess the social environment and act accordingly so that they are accepted as part of it. This allows the person to

> not only be an accepted part of the social environment but also influence it. It involves putting what the person knows into practice and is therefore based on procedure rather than fact (Sternberg et al., 2000).

Although the theory has often been used to consider the process of academic human development, consideration has also been given to members of society whose intelligence is not reflected through academic achievement. During later adulthood, work or academic related performances are not a useful measurement of practical intelligence and therefore it has been suggested that a person's abilities regarding daily tasks and social competence reflect their ongoing practical intelligence. Likewise, practical intelligence should only be defined by tasks that are considered a part of a person's real life within their specific age or cohort (Willis & Schaie, 1986). Within the domain's examples the person living with dementia is often positioned in regards to their ability to complete tasks. A perception that the person living with dementia is unable to complete the task may then result in *a lesser person* position that places the person living with dementia within the boundaries of social incompetence and therefore lacking practical intelligence. In *no longer capable* a person living with dementia suggests that family members position her as unproductive and therefore unable to carry out daily tasks. This results in the person living with dementia positioning herself as *a lesser person* within the social environment by being in a 'lower' position than before (Robertson, 2013).

Although positioning examples are weighted towards the notion of practical intelligence, all elements of the triarchic theory are required in the application of knowledge. Sternberg (1999) argued that intelligence is constantly evolving and therefore supports developing expertise. A person may be labelled as an expert but this will also produce a requirement for that person to perform within that field for others to be convinced of their expert status (Sternberg et al, 2000). Although one person living with dementia in *an able person* now requires some assistance to cook they are still positioned as an expert by their family member (Purves, 2010) whilst another family member positions a person living with dementia as *no longer capable* by stating that they are unable to use money despite the objections of the person living with dementia (Roach et al, 2014). The concept of developing expertise is based around a progressive acquisition and consolidation of everyday skills that are required to maintain real life performance (Sternberg, 1999). To maintain one's practical intelligence it is imperative that one continues to develop expertise. Although a person may have always been able to use a kitchen appliance, the purchase of a new appliance results in a need to develop expertise in using this new model. The person is required to develop their practical intelligence as the means to address practical tasks alters whilst the social environment evolves.

The ongoing acquisition and consolidation required to maintain practical intelligence is immediately problematic for the person living with dementia. Biologically, the storage of new memories is impeded for a person with Alzheimer's disease. Acquisition and consolidation are memory functions which are adversely affected by the biological changes in the brain caused by the disease. Atrophy to the hippocampus, which is integral to the acquisition, consolidation and retrieval of memories, is a feature of Alzheimer's disease that has been illustrated through neuroimaging techniques (Schröder & Pantel, 2016). In Alzheimer's disease there is also degeneration in the basal forebrain cholinergic cells and the brain stem serotonergic cells. The loss of memory functioning may also be related to this combined degeneration (Riekkinen & Riekkinen, 1995). Therefore, although the person living with dementia could attempt second order positioning against those who negatively position them regarding practical ability they are also negated by the neurological damage that adversely affects their ability to evolve within the theory of practical intelligence.

To be viewed as *an able person* within the theory of practical intelligence it is not enough for the person living with dementia to maintain their *current ability.* An expectation that the social environment will change also produces a need for an individual's intelligence to evolve. Cognitively this may not be acceptable or possible for the person living with dementia although family positions that suggest the person living with dementia needs information to be withheld from them (Purves, 2010) will also limit the process of adaptation. Although positions within the *practical ability* domain are predominantly concerned with practical intelligence in the triarchic theory, there is a continuing need for the person living with dementia to also rely on analytical and creative intelligence if they wish to evolve and therefore maintain positive positions regarding their *practical ability*. Despite the demands on the person living with dementia to use all components of the triarchic theory, this is not reflected in the positioning by themselves or others were the focus remains predominantly on practical ability.

A lack or a perceived lack of practical intelligence creates *lesser person* positioning as being unable to successfully maintain one's practical abilities can result in being positioned as inadequate (Clarke & Bailey, 2016). The need to evolve is addressed in the family member's positioning who addresses the person living with dementia as a pupil (Shakespeare & Clare, 2005). In this position there is an acknowledgement that the person living with dementia has a continued need to learn and adapt. However, the language also creates an infantilising *a lesser person* position that also negates the person living with dementia's opportunity to positively position themselves regarding their ongoing *practical ability.*

Although the limited occurrences of current ability positioning by other groups does suggest a lack of acknowledgment for people living with dementia's ongoing abilities it may also represent positioners who are viewing ability within a social environment that is immediately exclusive to people with cognitive deterioration.

Internal values analysis

There is a clear numerical and percentile difference between positions provided by people living with dementia when compared to other groups, regarding the *positive* and *negative core* themes (see Charts 11 and 12). Examples within the *internal values* domain express the personality of the person living with dementia whether in regards to who they believe they are or how others perceive them. The majority of *internal values* examples relate to the positioner's perception of the person living with dementia's personality. *Positive core* examples tend to suggest that there has not been a change regarding the person living with dementia's personality or values whilst examples from the *negative core* illustrate undesirable personality changes.

Although addressing an undesirable personality does negatively position the person living with dementia it may also be a logical progression of the positioner's perception of the person living with dementia. It is not uncommon for people living with dementia to experience changes in their personality and therefore *negative core* positioning cannot be immediately labelled as malignant. Changes in personality have been observed in people living with dementia prior to the onset of cognitive deterioration (Cipriani, Lucetti, Danti, Ulivi, & Nuti, 2015). Case histories of seven people diagnosed with frontal lobe type dementia displayed significant changes in personality and social misconduct despite the person living with dementia having minimal neurological damage and good physical health (Neary, Snowden, Northen, & Goulding, 1988). Although people living with dementia in the literature overwhelmingly positioned themselves within the *positive core* of the *internal values* domain it could be argued that these positions were created prior to the onset of personality change or that neurological changes to the frontal lobe could cause a lack of empathy with others and therefore the person living with dementia lacks the insight into the effects of their behaviour. The occurrence of passive, agitated and self-centred behaviours has also been measured as occurring in 11% of people with mild Alzheimer's disease which increased to 50% for people in the severe stages of the illness (Rubin, Morris, & Berg, 1987). The example of the person living with dementia as 'self-centred' (O'Shaughnessy, 2010) is provided by a family member who could argue that the same position is absent in the positioning by the person living with dementia due to the nature of the position's meaning.

Despite the neurological evidence regarding personality change in people living with dementia the disparity between the two core themes when positions are provided by either people living with dementia or others remains remarkable. Examples of the person living with dementia being positioned as foolish (Liu et al, 2008) or interfering (DeMedeiros & Sabat, 2013) are included in the *negative core* but the language used equally suggests that the positioner's attitude towards the person living with dementia is inherently negative. The negative preconception towards people living with dementia that would influence *negative core* positioning reflects the findings of a survey concerning the British public's attitudes towards dementia (Public Health England, 2015) when 62% of respondents stated the belief that people living with dementia can often be violent and aggressive. Qualitatively the survey suggested that the findings may not be overtly negative as it could reflect that people living with dementia are being welcomed into society and therefore this type of behaviour may be observed more frequently by the general public. However, this rationale would be unpalatable to those who wish to remove negatively labelling language concerning dementia and represents a significant overestimation regarding incidents of violence and aggression involving people living with dementia.

Several examples within the *internal values* domain are provided as labels which are often observed in nursing and medical case notes. The experience of a person living with dementia who is unable to leave a mental health ward due to being under a section of the mental health act (Government of the United Kingdom, 1983) but who believes that they must attend their place of work can be depersonalised through *negative core* labelling language. The person living with dementia may believe that they are still employed and need to attend work. If they fail to do so they will lose their job which will have ramifications on their ability to provide for their family. Although the person living with dementia is told that they are retired and do not have to attend work the attempt to orientate the person living with dementia is unsuccessful who still wishes to leave. Despite several attempts to leave the person living with dementia is constantly stopped from doing so and becomes frustrated and angry towards the healthcare staff. The fear of losing their job and being unable to provide for their family results in the person living with dementia acting aggressively towards the healthcare worker. This is an extremely complex and emotive situation although it does suggest that the person living with dementia's *positive core internal value* that they need to support their family and their belief that they should be reliable are intact. However, incidents such as this may be recorded in case notes using negative labels – 'the person living with dementia was disorientated and aggressive', that display no insight into the actual experience of the person living with dementia. Although for others the person living with dementia may be displaying socially unacceptable behaviour, for the person living with dementia traits of their premorbid personality remain.

An individual's personality traits are a reflection of their *internal values*. The trait theory of personality is a mechanism to explain behaviour. In this theory, human traits are identified to understand personality, actions and emotions. Allport (1937) initially recorded 4000 possible traits although subsequently other theorists have reduced this number (Goldberg, 1990) whilst others have questioned the feasibility of naming all traits (Grice, Jackson, & McDaniel, 2006). The identification of traits has led to two approaches, the idiographic and the nomothetic. The idiographic approach believes that people are unique and therefore traits may be dominant or only be possessed by one person. The nomothetic approach suggests that people all share the same traits but to different severities. In this approach, people remain unique although traits are shared. The idiographic approach allows an understanding of new traits and variables whilst the nomothetic approach would allow these variables to be compared in different people (Falk, 1956).

Allport (1937) suggested that human traits could be categorised under the following domains:

- Cardinal traits
  These traits are rare and do not tend to develop until later in the person's life. They dominate the personality of the individual and often other people will refer to the person on the strength of this trait (e.g. the person has a Machiavellian personality).
- Central traits
  These encapsulate the major characteristics of a person which may be used by others to describe them. They provide the foundations of an individual's personality (e.g. the person is kind and considerate).
- Secondary traits
  These are less consistent traits that may only arise in certain situations. Therefore, rather than being viewed as consistent personality traits they could be regarded more as attitudes or a small aspect of a personality (e.g. the person does not like to talk in front of an audience).

For a person living with dementia it could be argued that although cardinal and central traits may be altered by the neurological processes of dementia, the reliance on secondary traits may become increasingly dominant. Unfamiliar situations are more likely to occur for the person living with dementia. Situations may appear unfamiliar due to a lack of orientation or a memory impairment. Likewise, malignant positioning by others may result in the need for protective second order positioning that has not been required before. In these circumstances the secondary traits of the person living with dementia may be intact but are now viewed by others as central traits due to their more frequent occurrences. If a person becomes angry due to being negatively positioned by others but is rarely positioned in this way they are unlikely to be viewed by others as a hostile person. However, if the person has dementia and negative positioning becomes more frequent, occurrences of their anger also increase which will then inform the 'hostile' positioning by others. A secondary trait, such as anger or aggression, may be viewed by others as part of a *negative core* and therefore perceived as a central trait. When describing the person living with dementia to others, the secondary trait may also be promoted to cardinal trait status. A person living with dementia who has responded to a physical intervention with physical aggression may have their personality labelled as 'aggressive'. Positioning examples of the person living with dementia as troublesome (Forbat, 2003) and problematic (DeMedeiros & Sabat, 2013) may provide a negative cardinal personality trait if provided in isolation.

The greater prevalence of secondary traits may be influenced by the neurological processes caused by dementia but equally by the social environment. Allport (1937) suggested that both external and internal factors influenced human behaviours and personality. Phenotypes are external forces that effect how the person accepts the social environment or how the actions of others alter their behaviour. Genotypes are internal factors such as how the person retains information and then uses it during their interactions with others. Trait theory tends to emphasise a biological approach to personality and therefore leans towards a genotype explanation for personality traits. Phenotypes have greater recognition in social learning theories in regards to personality development (Bandura, 1986). In a purely biological model of dementia, the genotype theory would explain why changes in the person living with dementia's personality traits and therefore, how their *internal values* occur. However, the recognition of malignant social psychology and positioning demands the acknowledgement of the social environment's influence on the person living with dementia's personality traits. Although, personality changes are a biological symptom of dementia, the reliance on *negative core* positions by others perpetuates the person living with dementia's need to rely on secondary traits which in turn may reinforce *negative core* positions.

An evolving self analysis

The four themes in the positioning by others within the *evolving self* domain are separated by comparatively smaller margins in comparison to themes in other domains. For people living with dementia, the *maintaining self* theme dominates the position within the literature (see Chart 14). As previously suggested, the high occurrence of *maintaining self* positions in the examples from people living with dementia may be attributed to the majority of interviews with people living with dementia being conducted in the earlier stages of the disease and therefore when a sense of maintained selfhood may be more strongly retained. For other groups, the insight of the person living with dementia or current stage of dementia has less bearing on their applicability for interview resulting in higher occurrences of positions that suggest a *changing* or *disintegrating self.*

The importance of self and its relation to dementia can be traced back to the case notes of Alois Alzheimer (1864 – 1915) who recorded his interviews with Auguste Deter (1850 – 1906), the first person to be diagnosed with Alzheimer’s disease. Auguste Deter had been admitted in 1901 to the Frankfurt am Maine insane asylum. On November 26th of that year, Alzheimer asked Auguste Deter to write her name. She was able to write ‘Mrs’ but was unable to complete her name, famously stating ‘I have lost myself’ (Maurer, Volk, & Gerbaldo, 1997). The loss of one’s name illustrates the fear of losing oneself completely as described by Christine Bryden (2005). Bryden wrote openly about her fears regarding the later stages of dementia and particularly the foreboding expectation that there would be a time when she would not know who she was, not know her family or her God. However, Bryden countered this fear by suggesting that although her sense of self would inevitably change due to dementia, her true self would remain intact. She described this true self as the version of herself that delights in the beauty of the outside world or relates to God. Bryden described the true self as living in the present and therefore a person living with dementia should accept the *evolving self* but be reassured that this does not deny them the ability to positively experience their present self.

Bryden’s accounts of positively living with dementia support Kitwood’s (1997) hypothesis that there are two extreme reactions to a diagnosis of dementia. The first reaction is that the person living with dementia is very aware of what is happening and is therefore more likely to have a benign experience during the progression of dementia. The second extreme is that the person living with dementia has very little or no insight into what is happening which results in the prominence of raw emotions over reasoning. This results in the person living with dementia blaming others or possibly developing delusions such as the belief that people are stealing from them when they misplace possessions. Other groups who provide *unwanted self* positions are more likely to do so when the person living with dementia reacts to their diagnosis from the latter extreme, although this is perhaps equally indicative of the positioner's lack of insight and negative reaction to the diagnosis.

The *unwanted self* position appears to be informed by other's reactions to the behaviour of the person living with dementia which is perceived as negative. This behaviour, however, may also be considered part of the *evolving self*. Whilst healthy a person is less likely to exhibit behaviour determined by feelings of anxiety and fear (Maslow, 1954), for people living with dementia, feelings of anxiety are a considerably more frequent occurrence (Porter et al., 2003) which inform a change in behaviour. Equally, the hierarchy of needs acknowledges the individual's need for self-actualization which suggest that 'what humans *can* be, they *must* be' (Maslow 1954, p.22). This need is evidently unfulfilled for the person living with dementia positioning themselves within the *disintegrating self* theme who states they are lacking purpose but wanting purpose (Sabat, 2008). The denial of self-actualization through the positioning of others is then reflected in the family member's *unwanted self* statement, 'He resents my taking over his life completely' (Sabat, 2008). The acknowledgment by the family member that they have completely taken over the person living with dementia's life denies the possibilities of what the person living with dementia can be whilst the description of his resentment regarding this situation creates a position for him as an object and objectionable.

As the self evolves, concerns regarding losing one's previous self should not be regarded as an irrational fear as the time may come when the person living with dementia does eventually lose the self-awareness of who they are and with this, loses the sense of their individual identity. It is therefore the responsibility of the caregiver to support the person living with dementia to maintain their sense of self for although self-awareness may have altered this does not mean that there is an actual loss of the person living with dementia's identity. The task of maintaining the person living with dementia's sense of self, however, is not always embraced by caregivers who often feel that this maintenance is false and uncomfortable for them (Radden & Fordyce, 2006). Therefore, although caregivers may have the intention to uphold the person living with dementia's sense of self, their verbal positioning may reflect their frustration and sadness caused by having to do this and thus informs *disintegrating* and *unwanted self* positions.

The *changing self* position created by a family member in the example, ‘seeming normal, but not being the same’ (Robertson, 2015) does not suggest that the person living with dementia is engaging in behaviour that would be deemed unusual unless you previously knew them. It may also be that the person living with dementia is changing less than the positioner recognises. There is a tendency to think of people living with dementia as having a historical self and a self with dementia. As people living with dementia often refer back to longer term memories it may be more prudent to consider the person living with dementia as living in the historical self but in a different set of circumstances. Baldwin (2009) provides the example of a person living with dementia in a nursing home who would remove his clothes every afternoon. Previously the person living with dementia would have done this every afternoon to go swimming in the river. In the nursing home environment this behaviour was seen as challenging but in fact was a continuation of his historical self that required an environment to evolve to meet his needs.

William James’ (1842 – 1910) theory of self divided the concept of selfhood into three individual selves that could potentially cause conflicts within the same person. He described the three selves as the:

- Material self
  This includes the physical self but also considers our physical attachments. This may include clothing or specific objects of importance to the person. It also includes the person’s attachment to others as the material self will alter following the loss of a family member or significant person.
- Social self
  There will be numerous social selves depending on the situation the person finds themselves or in regards to the other person or people they are with. A different social self may exist for every other person that the individual meets. The social self is also likely to be influenced when the person is placed in a group who they hold with high regard.
- Spiritual self
  In the Jamesian theory, the word spiritual is used for what would now be more commonly considered to mean psychological. This self directly relates to positions concerning *internal values* as it is concerned with notions of personality and beliefs. James referred to another form of self, the pure ego,

which is directly linked to the spiritual self and does not tend to change through the person's lifespan (Comello, 2009).

The person living with dementia's material self, particularly through personal attachment, is upheld in the people living with dementia example, 'a grandmother' (Purves, 2010). This example provides a perception of the material self from the perspective of the person living with dementia which is not as clear in the examples from other groups. *Maintaining self* examples in other groups create the *normal* and *same person* position through a general recognition of selfhood, that they are the same person or that they are an ordinary person rather than through a recognition of personal attachment. Attachment examples are present, however, through the positioning of family members in the *different person* subtheme. Examples including 'this isn't the old Dad' (Phinney et al*,* 2013) and 'not my dad' (Sikes and Hall, 2016) act to illustrate not only a perceived alteration in the person living with dementia's material self but also the positioner's awareness that their own material self has altered in regards to their father. The influence of a changing material self combined with the continuously evolving social self may provide an explanation for the family member's *unpleasant* positions. These positions are dominated by family member examples which could suggest that the relationship created and altered in the material self, which is altered again by the social self may result in a profound negative effect on the relationship between the person living with dementia and their family member. The changes in the material self may result in the social self being more heavily influenced by the spiritual self when other concepts, beyond personal attachment, may have a greater influence on the relationship. Fitzpatrick and Winkie's (1979) interpersonal conflict study suggests that people will alter their approach to conflict depending on the other person's gender and the quality of the relationship they have with each other. If the latter is affected, a dependency on the former and other variable influences would result in altered approaches to conflict in people living with dementia with family members and vice versa. James (1890) suggested that pure ego, unlike the other variants of self, does not evolve but if the changes caused by dementia on the material, social and spiritual selves are recognised, the concept of an ongoing 'I' self or pure ego cannot be accepted without question. The person living with dementia questions the existence of the unaltered self through their own *different person* example: 'Self-image no longer matches reality (Davies, 2011).

Control over life analysis

The first principle documented in the Mental Capacity Act (Department of Health, 2005) states that ‘a person must be assumed to have capacity unless it is established that he lacks capacity’. The results of the scoping review concerning *control over life* suggest a clear disparity between how people living with dementia verbally position themselves regarding the level of control over their own lives and how other groups verbally position people living with dementia. Although there is a statistically significant difference between the results from people living with dementia and other groups the reasons for this could also reflect the nature of qualitative research in dementia. The person living with dementia involved in the studies from the scoping review are predominantly in the mild to moderate stages of dementia, remain capacitous and therefore verbally position themselves within the theme of *having control.* Likewise the other groups may not always reflect verbal positioning in relation to people living with dementia within this group and therefore when discussing people living with dementia who may be experiencing symptoms in the severe stages of the syndrome the dominant theme becomes *no control*. However, this theory does not account for the radical difference in verbal positioning between people living with dementia and other groups as many of the examples derive from the same studies and therefore often concern the same person living with dementia. Overall people living with dementia, within the literature, verbally position themselves within the theme of *having control* in 60% of all examples relating to the domain (see Chart 19). In comparison, other societal groups have an 80% occurrence of *no control* in their verbal positioning (see Chart 21). Rather than accept these occurrences at face value it is necessary to consider whether the disparity in these verbal positions exists due to positioner’s holding differing concepts of what is meant by control.

Rotter (1966) suggested that concepts of control could be identified through two beliefs, internal and external control. Internal control is concerned with events that are dependent on the individual’s behaviour whilst external control relates to events that are not dependent on individual action. External control suggests that events may be under the control of more powerful figures or authorities or may simply be very unpredictable due to the various behaviours of others during events. A belief in internal control is concordant with a belief in *having control.*

Battle and Rotter's (1963) American study of ethnicity and beliefs regarding control included black and white school age children and suggested that an individual's race could significantly affect one's beliefs concerning control. A higher belief in external control was displayed in lower class black children in comparison to their white contemporaries. In hindsight the historical setting of this research, which occurred at the heart of the civil rights movement in America when black people were treated unequally to their white counterparts, cannot be dismissed. At that time, using Weberian stratification (Gerth et al., 2013), black people in America were viewed by those with traditional authority as having less social power and rights than white people. Therefore a belief in external control at this time also reflects the current socio-political status of black people. In comparison people living with dementia, who can often appear absent in the model of Weberian stratification, may also be seen by others as having an inherent belief in external control. If other societal groups view the person living with dementia as *dependent* or *lacking ability*, the belief in external control for the person living with dementia is established which then supports a verbal position of *no control*.

The formulation of internal and external control was revised by (Rothbaum, Weisz, & Snyder, 1982) who considered that people who are exposed to external control beliefs will attempt to gain internal control. They conceived control as two salient processes that take place within four types of control mechanisms (Predictive, Illusory, Vicarious and Interpretive). Primary control is the attempt to alter the world so that it meets the person's needs and suggest that the person themselves is the greatest influence on control. Secondary control, similar to Rotter's external control, suggests that something more powerful has usurped primary control from the individual placing the person in a secondary control position. This revision influenced the development of a Life Span theory of Control (Heckhausen & Schulz, 1995) which examines the development, stability and management of primary and secondary control during a person's life.

The theory suggests that secondary control dominates the strategies used by people who are experiencing losses caused by ageing. People from a spectrum of age groups recognised forgetfulness and disorientation as possible age related losses (Heckhausen & Baltes, 1991). Such losses are viewed under secondary control as people have limited control over them. It was also evident that whilst people were able to view these symptoms and the loss of primary control in others they are less likely to recognise this in themselves. When this theory is applied to people living with dementia it could be rationalised that the high percentage of *having control* examples from the people living with dementia literature are occurring, not because of a continuation of control, but due to a lack of personal recognition by the person living with dementia of their symptoms and their loss of primary control. Bandura (1997) suggested that older adults also retain a sense of mastery by adjusting the domains or standards that they use to measure their competence as they grow older. Other groups who are now recognising the dominance of secondary control mechanisms on the person living with dementia's control over their life react by verbally positioning the person living with dementia as having *no control*, as a reflection of the loss of primary control. However, this assumption is dependent on the viewpoint that issues of capacity and insight must remain unimpaired for the person to retain any primary control over their life.

Legislation in Northern Ireland directly relates lack of capacity to lack of control. When a person is unable to manage their finances due to a lack of capacity an application for a 'Controllership' can be made, placing financial control for that person in the hands of a nominated 'controller' (Northern Ireland Courts and Tribunals Service, 2017). Control, however, is not exclusively in the domain of the fully capacitous. The example of the daughter who recognises that their parent with dementia is screaming because their needs are not met (Bourbonnais & Ducharme, 2013) illustrates that the people living with dementia who may lack the capacity or the ability to meet their own needs will use other means to make their needs known and therefore attempt to retain primary control. The authors suggested that such interactions displayed the potentiality for people with severe dementia to intentionally and purposefully reposition themselves within a care triad.

Under the Lifespan Theory of Control (Heckhausen & Schulz, 1995) the possible symptoms of dementia, including forgetfulness, automatically cause a loss of primary control. If this assumption is accepted all people living with dementia, or other people who may be experiencing similar symptoms, are automatically referred from a position of primary to secondary control. For people living with dementia, however, the results of the scoping review regarding how others position them in regards to *control over life* suggests that secondary control is not only caused by the symptoms but also the external control and assumptions of others. The person living with dementia may not recognise this change in control due to the lack of recognition of their symptoms, as previously suggested by Heckhausen and Baltes (1991), which aligns with Heckhausen and Schulz's (1995) theory that older people, who have experienced losses, are able to maintain stable perceptions of primary control whilst effectively using secondary control strategies. If the person living with dementia retains a perception of primary control this would result in higher occurrences of *having control* positions for this group. For other groups the emerging dominance of secondary control, that they may recognise in others but not themselves (Heckhausen and Baltes, 1991), results in higher occurrences of *diminishing* or *no control* positions.

Continued positions of *having control* by people living with dementia may be directly supported by the Life span Theory of Control (Heckhausen & Schulz, 1995) which suggests that people living with dementia may not realise that there has been any change and therefore retain a perception of primary control despite the increase of secondary control situations. The conflict between primary and secondary control is consistent with Rothbaum, Weisz and Snyder's (1982) theory that neither happen in isolation but that both are in a continual state of overlap and coexistence.

The verbal positioning related to *control over life* is primarily related to the positioner's belief regarding whether the person living with dementia is using either primary or secondary control. If the positioner believes that only primary control allows a person to retain *control over life* they are likely to apply positions to the person living with dementia relating to *diminishing* or *no control*. For the person living with dementia the use of secondary control strategies maintains *control over life*, including a perception of primary control, which creates verbal positions relating to *having control*.

Despite the people living with dementia group providing the highest occurrence of *having control* examples (see Chart 19) there are no occurrences regarding this theme regarding how people living with dementia feel they are verbally positioned by others (see Chart 20). In comparison there is almost double the amount of occurrences of *no control* examples between the self-positioning of people living with dementia and how they view other's positioning (n11 v n21). These occurrences challenge Heckhausen and Baltes (1991) assumption that we do not recognise losses in ourselves that we do in others. Within the literature there is clear disparity between how people living with dementia verbally position themselves in regards to *control over life* and how they view the positioning by others. This does not reflect a denial of change but rather an attempt to deny the manner in which they may be negatively positioned by other members of society.

Appendix 10: Recommendations

Recommendations for research

This thesis has contributed original research findings relating to AI and positioning theory. Through the process of conducting the study, several issues have been raised which would benefit from further research.

1. More research is required regarding the positive narratives of people living with dementia, including younger and older participants, as a mechanism to explore potential interventions that could support ongoing positive experiences.
   This study has found that the positive narrative experiences of people living with dementia are a considerable source of generativity in the development of positive future visions. Crucially, the sharing of these narratives has also been shown to have a transformative effect on the person living with dementia themselves and other members of society who hear these experiences. There needs to be further exploration to establish how these narratives and co-created visions can be adopted to guide the development of health and social care interventions that meet the ideals of people living with dementia.

2. Further explorations should be conducted to test the reconfiguration of the 4D model of AI and whether its generative and transformative potential can impact on participant behaviour in different phases.

   This study proposed a reconfiguration of the 4D model with people living with dementia engaging the phases of Discovery, Dream and Design, whilst participants in three natural discussion groups, representing different social groups in society, were expected to Deliver the intended outcomes. This was a novel application of the methodology, which was supported by the outcomes suggesting that the principles of AI could be transferred between phases and different participants. As a novel approach, further research is required to explore whether the methodological findings of this study can be replicated when attempted with other participants. This approach to the methodology may promote the inclusion of people who would otherwise be unable to engage with the four phases. Research studies should also consider whether the methodology can be successfully reconfigured further, with phases involving participants in differing phases, beyond the scope of this study.

3. The Balancing Framework has been demonstrated as a novel method of conducting and displaying positioning theory analysis. This framework should be tested further with more extensive discourse, unrelated to case study materials.

   The Balancing Framework was developed through the Discovery and Dream phases of AI, following a thematic analysis of the discourse of people living with dementia. It was successfully applied to the discourse of narrative discussion groups to evaluate whether their positioning of people living with dementia had moved closer to the ideal vision of people living with dementia following the viewing of the AI outcome. The discourse in these groups was driven by fixed questions using brief case studies. The transferability of the framework should be tested by using it to analyse open discourse to explore whether the themes identified during AI are also appropriate for exploration outside of the study. Studies should consider health and social care discourse in dementia based forums to explore the application of the Balancing Framework at a wider level.

4. The Balancing Framework is a novel approach to positioning theory. Further Balancing Frameworks should be developed to analyse other lived experiences.

   The Balancing Framework was successfully applied to analyse discourse in the context of the desires of people living with dementia engaged in the inquiry. The Balancing Framework provides a clear visual analysis of positions within a defined context. Studies using positioning theory should look to adopt the development of the Balancing Framework using the Discovery and Dream phases, particularly when looking at clearly defined discursive contexts. The generative outcome of these two AI phases provides a unique insight into the lived experience of people involved in the inquiry and the development of Balancing Frameworks allows for clear outcomes to be identified and presented. These explorations should look to establish whether this approach is a valid mechanism to develop frameworks for positioning analysis or if the outcomes are novel to this study.

5. Mitigation for the barriers faced by participants to allocate positive positioning require further exploration.

   The study identified experiential barriers (emotional and practical) and positioning identities, which could impact on the ability of speakers to position people living with dementia in the manner proposed during the AI. Whilst the study argues that the emotional and practical experiences of participants must be respected and the lack of positive positioning does not suggest a malicious intent from the participants, it would be nihilistic to the critical humanist perspective of this thesis to take a resigned perspective to this finding. Whilst the AI outcome in this study was not observed to remove all stigmatising attitudes towards people living with dementia in participants, the recognition of these barriers serves to act as a catalyst for further explorations of these and the facilitators. The variance in malignant positioning between the societal groups in the study outcomes and the scoping review, suggests that differing research perspectives to address these barriers may be required in further studies. Any findings, which could potentially overcome these barriers should be shared and enacted in practice, education and policy developments.

6. More research is required to understand the emotional impact of caring for people living with dementia on healthcare workers.

   This study proposes that the practical experience of healthcare workers can act as a barrier during discourse to allocate positive positions as defined by the AI outcome. This finding does not deny the potential emotional impact of this caring role on this group. However, the results of this study are currently congruent with the current limitations of available research, with little exploration of the emotional impact of caring on this group. Healthcare workers are expected to deliver caring and compassionate care but dementia care is also fraught with emotional challenges. A greater understanding of the emotional impact of caring for people living with dementia on healthcare workers is required if senior service leaders are to provide this group with appropriate support and supervision.

7. A longitudinal follow-up study should address whether the changes in positioning are observed beyond the discourse of the case studies. The study should explore whether the study outcomes are also applied to real world actions to achieve social justice for people living with dementia.

   It is a significant limitation of this study that the desired changes in discourse are only analysed within the context of natural discussion groups exploring fictional case studies. Although positive change is observed within this context, it remains questionable whether these changes had any impact outside of the discussion group. At an academic level, it can be argued that AI has achieved a satisfactory degree of generativity and transformation but whether this transformation is applicable to the real lives of participants remains unknown. AI and critical humanism demand a social action, which means going beyond the confines of the study discussions and realising 'real world' change. This type of longitudinal study would benefit from post-doctoral study.

8. Further AI film projects should include younger and older people living with dementia to measure the impact of the outcomes in relation to the demographics of participants.
   Whilst this thesis explored the applicability of AI when used with people living with dementia, the group who consented to the study were considered younger people living with dementia. Further studies should include both younger and older people living with dementia to analyse whether the age of participants is demonstrated to affect the use of AI and the positioning outcomes of natural discussion groups.

Recommendations for policy

1. Younger people living with dementia have conceptualised an ideal vision of the future in relation to their positioning by members of society. Policy makers should focus on these visions when developing and applying dementia related policies.

   This study has presented a vision, co-created by people living with dementia, describing the behaviours of people in an ideal world relating to positioning theory. Whilst the continued involvement of people living with dementia and their advocates in the design and implementation of policy must be enacted, this vision should be adopted during policy design when considering the purpose of new initiatives. It is unacceptable that people living with dementia describe regular experiences of malignant positioning throughout their experience with different societal groups. Policy makers should embrace the vision of people living with dementia presented in this study and collaborate with other people living with dementia to evolve this vision for specific contexts.

2. AI should be applied as a means to engage with underrepresented groups to identify and design outcomes, which should be adapted to inform policy and deliver social change.

   This inclusion of people living with dementia in AI has rarely been discussed in the academic literature. However, this study has illustrated the potential generative capacity of people living with dementia who engage in the AI process. On the basis of this success, the use of AI should be promoted when policy makers are working with underrepresented groups. AI has been illustrated as a supportive mechanism for people living with dementia to share stories and generate transformative ideas. The same principle should be applied to other members of society whose voices are otherwise rarely heard.

3. Policy drivers to address the social stigmatisation of people living with dementia are required.

   Whilst this thesis recognises that the need to tackle the stigmatisation of people living with dementia has been the subject of national and international policies and guidance (Batsch & Mittelman, 2012a; Department of Health, 2009; Welsh Government, 2018; World Health Organization and Alzheimer’s Disease International, 2012), it also concurs with Swaffer’s (2014) concerns that ‘dementia friendly’ initiatives may potentially be used to conceal underlying malignant behaviours and attitudes about people living with dementia. Policy makers should look towards positioning theory as a mechanism to go beyond an aesthetically pleasing use of language, to consider the true impact of policy on the lived experiences of people living with dementia.

4. <u>Policy makers must include people living with dementia in the development and revision of initiatives. This involvement should include an appreciative stance, with involvement supporting a positive experience for people living with dementia.</u>

   The involvement of people living with dementia in the development of relevant policy is now accepted as a necessary component of designing new initiatives. This study has illustrated the generative benefit of encouraging narratives, which share positive experiences and outcomes, rather than only focussing on the deficits of current policy and services. Policy makers should adopt this appreciative stance to support the generation of new initiatives. Adopting the appreciative stance should also support positive feelings for people living with dementia involved in the process.

Recommendations for practice

1. Hearing experiences of dementia through the voices of people living with dementia of all ages, is crucial for health and social care staff.
   The outcomes of the positioning analysis illustrate that hearing the perspectives of people living with dementia can result in positive changes in the discourse of healthcare workers. However, research suggests that the potential for healthcare workers to engage in meaningful dialogue with people living with dementia is often lacking and care is typically task or safety focused, rather than centred on the person’s experience (Moyle et al, 2011; Clissett et al, 2013). In this study, healthcare workers were observed to alter their positioning of people living with dementia following the AI outcome. Healthcare workers must reposition their own perspectives of how they engage with people living with dementia and through hearing their voices, reposition the people living with dementia themselves.

2. The voices of people living with dementia should be included in local health and social care developments.

   This recommendation is a continuation of the previous point and is aligned to the recommendations for policy. If an ideal vision of the future is to be achieved, people living with dementia at a local level must be empowered to engage in health and social care initiatives. The appreciative stance should be adopted as a mechanism to understand how things should be, rather than providing a platform to describe what is wrong.

3. The education of health and social care staff should look beyond 'dementia friendly' labels and consider the social impact of language on people living with dementia.

   Although a framework for education and training exists within Wales (Care Council for Wales, 2016) and was informed by an Appreciative Inquiry approach, there is no formal provision of how education and training is delivered. In this framework, health and social care staff working with people living with dementia are expected to achieve a 'skilled' level. This includes addressing the social stigmatisation of people living with dementia, with outcomes based on the Equality Act (2010). This includes recognising and challenging the discrimination of people living with dementia. This description aligns with the critical humanist approach of this thesis, with inhumane practices requiring intervention. The barriers and facilitators for positive positioning illustrate the requirements for dementia education to move beyond the simplicity of 'dementia friendly' language and include education regarding how the experience of health and social care may impact on our ability to positively locate people living with dementia within discourse during practice.

4. The Balancing Framework should be applied to consider discourse in health and social care practice.

   The Balancing Framework provides the opportunity to analyse spoken and written language. Malignant social psychology (Kitwood, 1997) is one of the observed features of Dementia Care Mapping (Bradford Dementia Group, 2005), which involves the observation of health and social care practice with an intended outcome of enhanced person centred practices. The Balancing

Framework can be applied to written case notes and the discourse of health and social care practice to identify malignant positioning (Sabat, 2000). This analysis should be included in dementia education programmes to encourage health and social care practitioners to reflect on whether their own discourse is potentially malignant for people living with dementia.

Recommendations for education

1. <u>People living with dementia should be included in the teaching of health and social care students.</u>

   Similar to previous recommendations for health and social care workers, the voice of people living with dementia should also be heard in health and social care programmes at all educational levels. There is a potential within education that participants may not have experienced the practical and emotional barriers to positive positioning of their qualified peers. Including the voice of people living with dementia, alongside an understanding of malignant positioning, will provide a basis for students to understand the visions of the ideal world, prior to their qualified professional practice.

2. <u>AI should be embraced by health and social care educators to support positive reflections with their students.</u>

   The AI process in this thesis was illustrated to have considerable generativity and transformative potential. The process should be introduced to health and social care programmes at all educational levels to support them to develop positive initiatives in practice and to consider as a non-deficit based model of reflection. Reflective practice skills must be developed during pre and post registration education to develop registered nurses who practice autonomously, safely and effectively (Oluwatoyin, 2015). The AI methodology has great potential to inform practice and organisational development and is a skill, which this thesis advocates for those graduating into health and social care professional roles.

3. The education of health and social care students should look beyond ‘dementia friendly’ labels and consider the social impact of language on people living with dementia.

This point aligns with recommendation 3 for practice, with dementia training for health and social care students at all educational levels also requiring alignment with the Good Work framework (Care Council for Wales, 2016), whilst drawing attention to the barriers and facilitators, which influence the positioning of people living with dementia.