

Declaration

I, the undersigned, hereby certify that this material, which I now submit in fulfilment of a M.Sc. degree, has not been previously submitted as an exercise for a degree at this or any other University, and is, unless otherwise stated, entirely my own work.

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Using the Implicit Relational Assessment Procedure to Measure Dementia Stigma



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Abstract

Stigma towards people with dementia is a major barrier to diagnosis, intervention, and support. Research examining dementia stigma largely relies on explicit measures. This project aimed to develop the Implicit Relational Assessment Procedure (IRAP) as a measure of dementia stigma, and to compare levels of implicit and explicit biases across groups of non-careworkers populations versus care-workers. Forty-nine participants took part in the experiment; data from nine participants were excluded due to IRAP exclusion criteria. The final sample consisted of 23 non-careworkers, and 17 carer-workers. Participants completed an IRAP, the Dementia Attitudes Scale (DAS), the Fraboni Scale of Ageism-Augmented, the PRISM-PC Dementia Screening Subscale, and the Depression, Anxiety and Stress Scale (DASS). Care-workers also completed the Maslach Burnout Inventory (MBI) and the Staff Experience of Working with Residents with Dementia-Questionnaire (SEWRD-Q). Results indicated there was no significant difference on the IRAP between groups. Groups did not differ significantly in relation to questionnaire measures. There was no significant correlation between IRAP scores and questionnaire measures. Low statistical power was identified as a specific limitation in interpreting results. The results and implications for future research are discussed.

Contents

Chapter 1 -- Introduction	p.2
Chapter 2 – Experimental analysis of Dementia Stigma	p.28
Chapter 3 – Discussion	p.49
References	p.66
Appendices	p.81

CHAPTER 1

General Introduction

Using the Implicit Relational Assessment Procedure to Measure Dementia Stigma

Dementia is a progressive neurodegenerative condition characterised by deterioration in cognitive functioning across a number of domains including memory, executive function and attention (Greene, Hodges, & Baddeley, 1995). Dementia is also related to behavioural and psychological symptoms (BPSD) including depression, aggression and wandering; and leads to deficits in activities of daily living (Grand, Casper & MacDonald, 2011). The term ‘dementia’ is also used as an umbrella term that relates to the symptoms of the disease or condition. There are many different types of dementia; the most common type is Alzheimer’s disease. Other types of dementia include vascular dementia, fronto-temporal dementia, dementia with Lewy bodies, and Korsakoff’s syndrome. Research has focused on neurological, contextual and genetic factors associated with the onset of dementia; however no definitive cause has been identified (Cahill, O’Shea & Pierce, 2012). Although treatments with medication such as acetylcholinesterase inhibitors have been associated with mild improvements in cognitive function and behaviour (Winslow, 2011), a cure has yet to be identified. The risk of dementia rises significantly with age, with about 70% of all dementia cases occurring in people over 75 years old (Fratiglioni et al., 2000).

Dementia in Ireland

Analysis of Census data suggested that in 2011, there were roughly 47,849 people living with dementia in Ireland (Pierce et al., 2014). Approximately two thirds of those were female, while the majority of cases of early onset dementia (under 65) were male (Pierce et al., 2014). It is estimated that there are roughly 4,000 new cases of dementia arising in Ireland yearly; and based on predictions of rates of population growth, fertility and migration, the number of people with dementia in Ireland is estimated to grow to approximately 60,000 by 2021; 147,000 by 2041; and potentially reaching 150,000 by the year 2046 (Pierce et al.,

2014; Cahill et al., 2012). Census data estimated that 65% of all of those living with dementia were community dwelling; and of younger people with dementia, 85% live within the community (Pierce et al., 2014). The increasing numbers of people with dementia living in the community, coupled with the relatively limited treatment options, is likely to have significant implications for community support facilities. It will be important for the general public to contribute to the provision of supportive environments and dementia friendly societies. Differing perspectives of dementia in society, including the biomedical and social and psychological perspectives, are thought to shape how the treatment and priorities of individuals with dementia are viewed (Bond, 1999). Understanding these perspectives therefore is important in determining how dementia is viewed at a societal level.

The Biomedical Perspective of Dementia

The biomedical perspective characterises dementia under a disease model, concerned primarily with understanding its biological underpinnings and how it can be treated (Kitwood, 1997). Lyman (1989) detailed three primary areas that characterise the biomedical perspective on dementia: (1) that dementia is an abnormal and pathological illness, (2) that dementia progresses in stages and is organic in its aetiology, (3) and that dementia can be diagnosed using biomedical assessments. Essentially the biomedical perspective on dementia suggests that impairments in cognitive functioning that symptomatically characterise dementia are the result of neurodegeneration caused by the pathology of the disease (Purves et al., 2008; Innes & Manthorpe, 2012). The principle features of this neurodegeneration are a general loss of neurons and neurotransmitters leading to brain atrophy; collections of intraneural cytoskeletal filaments called neurofibrillary tangles; and extracellular deposits of amyloid in plaques (Purves et al., 2008). This perspective of viewing dementia as purely a biological disease has existed within research and treatment for roughly the last century (Dillmann, 2000).

The continued acceptance of the biomedical perspective on dementia has been very beneficial: it has shaped how dementia is treated; has led to vast advances in research on pharmacological interventions and to important developments in our understanding of how the condition affects the brain (Kitwood, 1997); and has influenced government policy in relation to care and treatment of people with dementia (Innes & Manthorpe, 2013). Critics have argued however, that the biomedical perspective has constrained how dementia is conceptualised. Primary diagnostic criteria rely on biomarkers for dementia and Alzheimer's disease which do not correlate with the majority of research (Garrett and Valle, 2016). A primary focus on biological correlates as a benchmark for diagnosis and on the neural pathology of the illness ignores the social, psychological and contextual factors that influence or correlate with the illness (Kitwood, 1997).

Social and Psychological Perspectives of Dementia

More recently, there is a growing trend towards viewing dementia in terms of the social and psychological elements that characterise the condition (Grand et al., 2011). This perspective attempts to move away from a traditional disease model of dementia, to view dementia instead from an embodied and social perspective (Sabat, 2001). This movement within the research literature allows for wider social context when considering the condition, and argues for the implementation of a social model of disability in viewing dementia, as opposed to a disease model (Sabat, 2001). The outcomes of social and psychological perspectives of dementia have led to treatments which focus on behavioural and psychosocial interventions that are aimed at reducing disability and challenging behaviours, and improving quality of life and wellbeing (Clare, 2008; Sabat, 2001).

This perspective of dementia leads one to consider issues associated with cognitive processing and communications as an explanation for social disablement of individuals with

dementia; which may result in difficult behaviours (Algase, Beck, Kolanowski, et al., 1996). Algase and colleagues (1996) discuss how behavioural disturbances associated with dementia could be predicted by assessing the function of the behaviour within its context. This approach to the treatment of dementia is encapsulated within an area of research known as behavioural gerontology, which aims to examine the dementia from a behavioural perspective and to improve psychosocial outcomes through behavioural interventions (Burgio & Burgio, 1986; Skinner, 1983; Trahan, Kahng, Fisher, & Hausman, 2011). From this perspective, there is an attempt to link the behavioural disturbances which many individuals with dementia suffer, and the personal history of that individual. For example, Algase et al. (1996) argued that the behaviour of a person with dementia has been learned across life, however in the absence of the physical and cognitive capacities the individual once held, the behaviours now fail to fulfil the same goal, or function. Therefore, behaviours such as wandering should not be viewed as goalless behaviour, but rather as a learned response to functions such as searching for a preferred stimulus, responding to an environmental stimulus which has caused a curiosity in the individual (such as a noise or light), or a learned reinforcement through the act of moving one's body (Algase et al., 1996). This form of analysis attempts to move away from a traditional biomedical perspective which symptomises behaviours and maps them onto the illness; and instead aims to view the behaviour of an individual from a person-centred perspective, in relation to that person's wants and needs.

The most important result of the shift from the biomedical to social and psychological perspectives of dementia has been the move towards viewing dementia from a person centred standpoint. Person-centred treatments have been shown to result in greater quality of care and more willingness by the individual to receive treatment (Chenoweth, 2009). People with dementia have reported that traditional (i.e., medically focused) care led to feelings of a lack of respect, and a lack of independence and recognition of their autonomy (Bryden, 2002).

DEMENTIA & STIGMA IRAP

Person-centred care on the other hand focuses on the personhood of the individual and how best to improve the life of that individual. Many of the behaviours observed in dementia may be seen as adaptive, which can negatively impact one's cognitive functioning (Bryden, 2002). As such, it is suggested that person-centred therapies can aid in mitigating the effects of cognitive impairment in individuals with dementia (Bryden, 2002). It may be argued therefore that there is both a clinical and autonomous benefits to viewing individuals with dementia through a more person-centred approach. This can also be argued in terms of the ethical benefits for research, for example, viewing people with dementia as participants in research (social perspective) as opposed to subjects (biomedical model) (Dewing, 2002). The divergent perspectives on dementia have shaped and continue to shape society's understanding of the condition, and are of crucial relevance to understanding how public attitudes towards dementia form. In 2012, the World Alzheimer Report found that of 127 people with dementia and 1,716 family carers surveyed, 75% of people with dementia and 64% of carers felt that the public had negative perceptions (i.e., stigma) about dementia. Therefore, it may be argued that from both a treatment and individual perspective, the way in which those with dementia are viewed may be of great significance; however, a further element that must be considered in how those with dementia are viewed is public perceptions of dementia. In order that the breadth to which individuals' interpretation of the stigma towards them is realised, it is necessary to consider this in relation to literature analysing public attitudes towards dementia.

Public Attitudes Towards Dementia: Stigma

Stigma refers to negative *attitudes* and beliefs about individuals perceived as being different (due to a diagnosis, condition or illness) to oneself; these attitudes can lead people to respond negatively to, be prejudiced towards, avoid, or even fear the individual with the diagnosis. For example, individuals may assume that people with psychiatric conditions are

violent and dangerous (Disability Rights California, 2016; Dovidio, Major, Crocker & Heatherton, 2000). The modified labelling theory proposes that in the context of diagnoses, individuals may possess *biases* about people with a specific diagnosis (e.g., dementia). It is suggested that the influence of this label (e.g., dementia) can impact an individual's attitude towards others with this label, with the individual attaching the attributes of that label to a person with the diagnosis, leading to bias (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). It is well documented within literature that labels can have highly adverse effects on the individuals to which they are given (Corrigan, 2004) and can perpetuate stigma.

Research analysing public attitude towards dementia often provides mixed responses. Werner and Davidson (2004) found that in general, individuals tend to have a somewhat positive attitude towards those with a diagnosis of dementia. A public attitudes study demonstrated that only a small minority, 4%, of participants believed individuals with dementia are to blame for their behaviours (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). Werner and Davidson (2004), in assessing emotional responses of the general public to dementia patients identified frequent reports of individuals wanting to help those with dementia, seeing them as patients that needed to be cared for. While it may be argued that these are positive and empathetic attitudes, viewing people with dementia in such ways (e.g., helpless, dependent) may be problematic. Attitudes such as these can be deemed stigmatising and may be harmful. Indeed, research suggests a common stigmatising attitude towards individuals with dementia is that they lack awareness (Clare, 2003), which can be related to perceived dependency. More recent research has demonstrated that the general public tend to possess negative and even infantilising attitudes towards those with dementia (Jorm, 2000; McParland, Devine, Innes, & Gayle, 2012). Research from surveys found that individuals from the general public were significantly less willing to interact with people with dementia compared to people with mental health problems (Björkman, Angelman, & Jönsson, 2008).

This is concerning, considering that the general public tend to perceive individuals with mental illness as being incapable of independent living, lacking responsibility, and dangerous (Angermeyer & Matschinger, 2003; Corrigan et al., 2000).

Attitudes of Care Staff Towards Dementia

Another facet of attitudes towards those with dementia that should be considered is attitudes of those working with individuals with dementia. There is substantial evidence suggesting there is a disproportionately high level of staff turnover in jobs working with populations behaviours that are difficult to manage, such as nursing homes (Castle & Engberg, 2005). As such, attitudes of those workers, in the context of dementia, should be considered. It is estimated that more than 50% of residents of nursing homes have a diagnosis of dementia (Alzheimer's Association, 2007); and that 20-50% of people with dementia in nursing home care settings display frequent aggression and hostility (Hersch & Falzgraf, 2007). In general, nursing homes experience a high turnover of staff (Banaszak-Holl & Hines, 1996; Thomas, Mor, Tyler, & Hyer, 2013). Research shows that this turnover can, in part, be attributed to difficulties associated with severe resident behaviours (Lerner, Johantgen, Trinkoff, Storr, & Han, 2014). In one study, staff reported 15.6% of residents directed aggressive behaviours, including verbal (12.4%) and physical (7.6%) aggression towards them (Lachs et al., 2013). Nursing home staff have been shown to distance themselves from aggressive residents; have reported feelings of frustration and anxiety towards these residents (Draper et al., 2000); may be hindered from providing the quality of care they aim for (Aiken, Sermeus, Van den Heede et al., 2012; McGilton et al., 2014); and experience high levels of stress (Rodney, 2000). High levels of stress in turn lead to burn-out which can contribute to more negative attitudes (Åström, Nilsson, Norberg, Sandman, & Winblad, 1999). On the other hand, research shows that care-staff attitudes towards people with dementia can be positive (Kada, Nygaard, Mukesh & Geitung, 2009). In one study, high

levels of job satisfaction in care staff correlated with more positive attitudes towards patients with dementia, particularly attitudes focused on person centred care (Moyle, Murfield & Griffiths, 2011). Research supports that individuals who possess more positive, person-centred attitudes towards dementia tend to possess higher job satisfaction, which has been linked to a lower risk of turnover (Zimmerman, Williams, Reed et al., 2005). Interventions may be suggested to aid in improving attitudes of staff toward those with dementia through effective management (Zimmerman et al., 2005), which would ultimately lead to better care for those with dementia. Therefore one may suggest attitudes of those working with individuals with dementia may be of great relevance in analysing. Assessing and improving attitudes of care staff towards people with dementia is important as it has serious implications for the well-being of both carers and the people with dementia in their care.

Effects of Stigma

Stigma in relation to dementia can have far reaching negative effects. Reviewing the literature reveals difficulties faced by people with dementia across many aspects of their lives which can be linked to the stigma surrounding dementia. Stigma towards dementia can affect the individual on an emotional and personal level (Burgener & Berger, 2008; Scholl & Sabat, 2008), and can impact the individual's social interactions with their family members and those around them. Caregivers of people with dementia in Ireland have reported that dementia is still hugely stigmatised; they perceive that society does not want to engage with or hear about people with dementia, and this leads to feelings of desperation and a lack of support for both the person with dementia and their family (Cahill et al., 2012; Hastings, 2009). A major issue associated with stigma is that often people with dementia do not obtain a timely diagnosis or intervention; the person with dementia, and more often, family members who notice problems with memory and cognition, delay taking action due to the fear and stigma associated with the disease (Cahill et al., 2012; Iliffe et al., 2005).

The Impact of Stigma on Dementia Diagnosis and Treatment

Stigma towards dementia may have severe implications for early diagnosis and intervention (Batsch & Mittelman, 2012). Research has suggested that an average of three years exists between when initial symptoms of dementia are recognised within families, and when medical evaluation is sought (Haley, Clair, & Saulsberry, 1992). Reasons for this are suggested to include denial, lack of awareness and lack of trust in medical interventions (Haley et al., 1992). In addition, when a diagnosis is given, individuals often conceal the diagnosis and fail to seek assistance (Batsch & Mittelman, 2012). This is problematic as early diagnosis and treatment is integral for the successful implementation of interventions such as cognitive stimulation therapies (Moniz-Cook et al., 1998; Spector et al., 2003) and behavioural therapies (Teri, Logsdon, Uomoto, & McCurry, 1997). When a diagnosis is made there still may be issues around accessing appropriate treatments. Kramer (1997) found that family carers, specifically spouses, tend to display denial-typical behaviour surrounding their partners' diagnosis, and attempt to regulate emotional difficulty through emotional suppression, wishful thinking, and avoidant behaviours. Analyses of public attitudes towards dementia in relation to treatment have demonstrated that individuals tend to possess negative prospects towards the benefit of treatment for individuals with dementia (Björkman, Angelman, & Jönsson, 2008). Survey results reported that individuals responded significantly to say those suffering with dementia would "never recover" (Björkman et al., 2008). This demonstrates a public perception of a lack of value or necessity in treating those with dementia.

Analysis of general practitioner (GP) attitudes towards treatment of dementia suggests a low rate of cooperation of GPs within the community in relation to dementia (Ólafsdóttir, Foldevi, & Marcusson, 2001); difficulty in communications between GPs and specialists in relation to dementia detection (Ólafsdóttir et al., 2001); and difficulty in delivering the

DEMENTIA & STIGMA IRAP

diagnosis (Bamford, Lamont, Eccles, Robinson, May, & Bond, 2004; Clafferty, McCabe, & Brown, 2001; Mitchell, 2007). One study found that less than 50% of practitioners reported giving diagnoses to individuals showing signs of dementia; often referred to as a “conspiracy of silence” (Clafferty et al., 2001). The UK Department of Health reported in 2012 that as only about 46% of individuals living with dementia have received a diagnosis (Milne, 2010). GP’s are gatekeepers between the general public and specialised dementia care. As a result, issues such as GP’s lack of knowledge of dementia, fear of the disease, embarrassment about discussing the disease with patients, and an avoidance of delivering difficult news to long-standing clients all act as barriers to appropriate care (Iliffe et al., 2005). Interestingly, analysis of attitudes towards diagnosis in people with dementia and their carers demonstrate a strong positive attitude towards the value of diagnosis, with 98% responding that they would like to know if they were developing dementia (Pinner & Bouman, 2003).

The Impact of Stigma on the Person with Dementia

Due to the influence of the biomedical perspective on the cultural understanding of dementia, research tends to focus primarily on symptomatic analysis of dementia, and not on the subjective experience of those with a diagnosis of dementia (Bener & Cheston, 1987). Of research that has been conducted in this area, results indicate that the subjective experience of dementia is one that may be significantly impacted by stigma (Batsch & Mittelman, 2012; Burgener & Berger, 2008; Scholl & Sabat, 2008). Metaphors and ways of describing dementia used within society tend to link dementia with negative aspects of ageing, such as frailty, helplessness and dependency (Bener & Cheston, 1997; Hockey & James, 1993). These associations are often internalised and can serve as self-representations for people with dementia (Bener & Cheston, 1997). Stigma may not only impact how society treats individuals with dementia, and have social implications in relation to access to social facilities and appropriate healthcare; but individuals with dementia may also be at risk of

suffering emotionally or psychologically as a result of stigma, due to internalising stigmatising associations made about dementia. This commonly manifests in experiences of anxiety and/or depression.

Anxiety. As discussed previously, stigmatising attitudes can result in a lack of information or diagnosis being provided to the person with dementia. Older adults who experience cognitive decline will commonly experience some form of anxiety (Bener & Cheston, 1997; Jessen et al., 2014) but anxiety can be exacerbated by a lack of information provided to the individual, an unwillingness to be honest with the individual, and information which is withheld from the individual by their GP or healthcare professionals (Bener & Cheston, 1997). Those who have obtained a diagnosis often report relief if they had suspicions regarding their diagnosis (Mitchell, McCollum, & Monaghan, 2013); and any anxiety following a diagnosis tend to decrease over time (Mormont, Jamart, & Jacques, 2014; Smith et al., 2009). Families often believe they are protecting the individual from harm by avoiding providing the diagnosis (Cornett & Hall, 2008), however this avoidance is thought to take away from the autonomy of the individual (Mitchell et al., 2013).

As withholding information may be a cause of anxiety to the individual, this problem may be intrinsic to the cultural stigma discussed by Bener and Cheston (1997), in relation to dementia. As individuals with dementia are often described as childlike and dependent, a lack of autonomy of that individual may be seen, leading to family members and medical professionals withholding information from the individual. As this has been suggested to increase anxiety suffered by the individual, one may suggest that in line with the proposals of Mitchell et al (2013), provision of full information to the individual should be paramount in order to ensure their subjective experience of dementia is not hindered by anxiety. Carpenter and Dave (2004) suggest that sensitivity to individual differences should be crucial to providing a diagnosis, in relation to how the information is provided and by whom it is

provided. This may aid in tackling anxiety and ensuring respect and autonomy are provided to the individual upon receiving a diagnosis. Anxiety is a subjective experience of dementia, however it may be one that is heavily influenced by the stigma associated with the disorder. Stigma may lead to individuals feeling like their right to full information about their person is not being respected by those around them, and on a more personal level that they are not viewed as fully autonomous- thus significantly increasing anxiety (Carpenter & Dave, 2004; Mitchell et al., 2013).

Depression. Similar to feelings of anxiety, reports of depressive symptoms are common in people with dementia (Katz, 1998). Up to 25% of those suffering from dementia also experience symptoms of depression (Lobo, Saz, Marcos, D  a, & De-la-C  mara, 1995). In contrast to the reported reduction in anxiety associated with a diagnosis however, people suffering from depression who received a diagnosis of dementia responded more negatively and reported strong feelings of depression as a result of their dementia diagnosis (Jha, Tabet, & Orrell, 2001). While the causes of depression in dementia are many, they may be related to stigma and the subjective experience of dementia through feelings of grief or shame. Individuals with dementia may experience rates of shame or embarrassment regarding symptoms such as the loss of memory (Cotrell & Schulz, 1993). Furthermore, individuals may feel grief at the perceived losses that come with a diagnosis of dementia (Bener & Chaston, 1987). This is relevant when looking at how dementia is impacted by stigmatising attitudes, as one may suggest that the perceived negative outcomes of dementia, which may be internalised by the sufferer (Bener & Chaston, 1987), can have negative ramifications in relation to the subjective experience of shame or grief in relation to one's diagnosis of dementia.

Factors that Mediate Negative Attitudes about Dementia

Research shows that the peoples' perceptions regarding the severity of dementia, and behavioural or social difficulties associated with dementia may have a significant effect on the rate to which negative attitudes exist (Werner, 2000). In one study, negative attitudes towards dementia were primarily associated with fear and aggression behaviours (Werner & Davidson, 2004); while another study showed that challenging or aggressive behaviours can put the person with dementia at greater risk of neglect or abuse (Goergen, 2001). The perceived severity of dementia may even impact public opinion towards treatment. For example, positive public opinions were shown towards life-sustaining treatment in individuals with mild dementia; however the need for life-sustaining treatments was seen as less valuable in individuals with severe dementia (Williams, Dunford, Knowles, & Warner, 2007).

Information about dementia and level of understanding or knowledge may also mediate stigmatising attitudes towards people with dementia (Batsch & Mittelman, 2012; Cheng et al., 2011; Werner, 2000). The World Alzheimer Report (2012) attributes a lack of information and education about dementia as one of the primary causes of stigma. The report highlights how a lack of understanding can lead to misconceptions that result in the perpetuation of dementia stigma, and that this issue is prevalent in most countries (Batsch & Mittelman, 2012). In one randomised controlled trial (RCT), Cheng et al. (2011) assessed whether negative attitudes could be influenced by information that personalised individuals' suffering through the use of vignettes. They found that that even brief exposure to information about dementia led to a statistically significant reduction in stigma. Participants who had a relative or friend with dementia; and therefore had more exposure to dementia and knew more about the condition, showed less stigmatising attitudes than those who had no close relationship with a person with dementia. In addition, those who were younger and

more educated, and who thought dementia was treatable had more positive attitudes towards the disease (Cheng et al., 2011). Among professional care staff, those who have good knowledge of dementia and have received appropriate training have more positive attitudes (Moyle et al., 2011; Richardson, Kitchen & Livingston, 2002). Recommendations from the World Alzheimer Report (2012) on reducing dementia stigma include improving education and knowledge about dementia among individuals in the general public, and for formal and informal carers; and improving dementia training for healthcare professionals.

The above findings highlight the impact that stigma can have in relation to social responses, communication, relationships, diagnosis, and treatment of people with dementia. These findings also emphasise the importance of determining where stigma exists in society through accurate assessment of stigmatising attitudes. Accurate assessment of stigma can, in turn, determine whether interventions such as information and education are successful in reducing stigma.

Measuring Dementia Stigma

Research has long attempted to measure attitudes towards dementia, employing a variety of different techniques in order to do so. Such techniques primarily involve measures of explicit attitudes such as questionnaires, or qualitative analyses. A common questionnaire used in dementia attitude research is the Dementia Attitudes Scale (DAS; O'Connor & McFadden, 2010). The DAS has been applied across a number of experimental settings in order to assess individuals' reported attitudes towards dementia (Scerri & Scerri, 2013; George, Stuckey, & Whitehead, 2014). Further questionnaires have attempted to not only assess dementia attitudes, but to also examine factors which may influence responses about dementia. Such measures include the Fraboni Scale of Ageism-Dementia augmented (Fraboni; Philipson, Magee, Jones, Skladzien, & Cridland, 2012) which aims to assess the

rate of avoidance an individual may have towards dementia; and the Perceptions Regarding Investigational Screening in Primary Care (PRISM-PC; Boustani, Perkins, Monahan et al., 2008) which aims to assess how an individual would themselves respond to a diagnosis of dementia. In assessing attitudes of care staff who work with people with dementia, the Staff Experience of Working with Residents with Dementia-Questionnaire (SEWRD-Q; Åström et al., 1991) examines staff experience of working with people with dementia including contact with residents, expectations of others and the person's own expectations, feedback at work, and the work organisation and environment. The scale assesses areas potentially linked to burnout and their relationship to attitudes.

To date, the majority of research suggests that stigma towards people with dementia in the general public (Batsch & Mittelman, 2012; McParland et al., 2012) and among professional carers (Draper et al., 2000) is an issue; however assessment using explicit questionnaire measures has produced some conflicting results, i.e., other research has produced findings which suggest the general public may possess positive attitudes towards individuals with dementia (e.g., Crisp et al., 2000; Werner & Davidson, 2004; Moyle et al., 2011). Conflicting results in relation to dementia stigma have been argued to arise due to potential limitations of explicit measures. Such limitations are discussed by Blay and Peluso (2010) whereby they argue stigma toward dementia as measured by questionnaires may be subject to social desirability bias. Blay and Peluso (2010) argue that in questionnaires individuals may report more socially acceptable responses which may be misrepresentative of their true attitudes. As such, one may suggest the standard practicum by which dementia stigma is measured may not be entirely affective in assessing stigma. In order to further investigate dementia stigma, it has been suggested to be useful for researchers to consider a novel approach to measuring stigma.

A New Approach to Measuring Dementia Stigma

Stigma has been described as a negative attitude or biased opinion (Dovidio et al., 2000; Link et al., 1989). It might therefore be beneficial to look to the area of implicit attitude research in seeking a methodology that may complement existing explicit measures and provide additional information about stigma. Greenwald and colleagues, in his research on attitudes, has reported that individuals show implicit attitudes and beliefs that are often inconsistent with attitudes they willingly display on self-report measures (Greenwald, Banaji, Rudman, Farnham, Nosek, & Mellott, 2002). Responding on self-report measures has been shown to be influenced by socially desirable responding; the participant has time to carefully consider each response, and is more likely to respond in a way that they believe is acceptable as opposed to providing responses that reflect their true beliefs or attitudes (Greenwald et al., 2002; Nosek, 2007). Conversely, implicit measures are thought to capture responses that are immediate, automatic and less controlled (DeHouwer, 2006; Hughes, Barnes-Holmes & DeHouwer, 2011); with implicit attitudes defined as favourable or unfavourable feelings, thoughts or actions towards social stimuli (Greenwald & Banaji, 1995). Problems with measurement of such phenomena via introspection have also long been acknowledged in psychology, indeed as far back as Wundt. Considering the sensitive nature of assessing attitudes towards people with dementia, implicit measurement may provide a means of capturing additional information that is not influenced by social desirability. The most commonly used implicit measure is the Implicit Association Test (IAT; Greenwald, Banaji, Rudman, Farnham, Nosek, & Mellott, 2002), which is based on associations in memory. The Implicit Relational Assessment Procedure (IRAP; Barnes-Holmes, Barnes-Holmes, Power, Hayden, Milne, & Stewart) is a more recent development with a similar in design format, but is a behavioural measure with some distinct advantages in facilitating more nuanced measurement of implicit responding. The primary distinctions suggested within literature between IAT and IRAP relate to whether relations derived from the tests are absolute or

relative (Hussey, Thompson, McEnteggart, Barnes-Holmes & Barnes-Holmes, 2015). In order to develop an understanding of the IRAP and understand this distinction, it is necessary to discuss the IAT as a crucial measure in the influence of the IRAP. In order to interpret the distinction that the IAT may be a relative measure and the IRAP may be an absolute measure of implicit relational/associative responses, one must therefore initially be familiar with the methodology of the IAT and IRAP.

The Implicit Association Test

Much research into implicit attitudes has been developed out of the IAT, which assesses associations between paired concepts with a presented attribute. The IAT functions on a format of presenting object stimuli, being paired with oppositional associations, that are typically positive or negative in language (e.g., pleasant or unpleasant), that participants must respond to based on a presented rule (Greenwald, McGhee & Schwartz, 1998). The premise of the IAT is that highly associated categories should show higher rate of response than low associated categories, referred to as the associative attribute model (Greenwald et al., 1998). Research has assessed the validity of attribute stimuli (i.e., pleasant and unpleasant) in IAT analysis, and has suggested manipulation of the associative attribute model leads to variation in attitudinal responses (Olson & Fazio, 2004).

The IAT assesses the association between a target stimulus (e.g., flowers/insects), and an attribute stimulus (e.g., pleasant/unpleasant). The IAT requires participants to press keys to associate stimuli with left/right sections, across five phases. Initially participants are required to discriminate between target concept stimuli (e.g., separate pictures of either flowers or insects that must be discriminated into separate categories). Following this, attribute stimuli must be discriminated between into categories (e.g., variations of pleasant and unpleasant descriptive adjectives). Thirdly, participants are required to associate target

and attribute stimuli into either left or right (e.g., Right: flowers/positive; Left: insects/negative). Upon completion of this step, the target stimuli are swapped between left and right. Fifthly, associations are reassessed upon the left/right targets being swapped (e.g., Right: insects/positive; Left: flowers/negative; Greenwald et al., 1998).

While the IAT has had a major influence in the field of attitude research, there are some limitations to the procedure in terms of the information it provides. The IAT measures the relative strength of associations among the stimuli but does not provide information about the stimuli independent to or non-relative to one another (De Houwer, 2002). This means that results can only present responses relative to one another. Therefore as is previously mentioned on p.19, this suggests the IAT is a relative measure of implicit responding. When we consider this in relation to the example provided above, discussing insects and spiders, results could only present a response of attitudes to flowers relative to attitudes to insects. A result could not be provided within the IAT of whether the bias was a result of a strong/weak pro-flowers bias, a strong/weak anti-insects bias, or some combination of the two. As is suggested previously, this therefore is the primary distinction between the IAT and other implicit measures such as the IRAP. This has been suggested to be a limitation of the IAT (O'Shea, Watson, & Brown, 2016). There are many conceptual issues with this limitation, i.e., if the example is once again applied of insects versus spiders, in the case of interventions designed to change individuals' attitudes towards one target (e.g., insects), there is not specific evidence to suggest participants have a negative bias towards that target (e.g., insects), as distinct from a positive bias towards the other target (e.g., flowers; O'Shea et al., 2016). The IRAP attempts to compensate for some of the limitations of the IAT by employing a non-relative measure of implicit attitudes (Nicholson & Barnes-Holmes, 2012). The IRAP was devised within the theoretical framework of Relational Frame Theory (RFT; Hayes, Barnes-Holmes, & Roche, 2001). As has been previously discussed, there is a primary

distinction between the IRAP and IAT in relation to how implicit responding is interpreted (i.e., as being relative or absolute). Despite this, in order to comprehend this distinction in suggesting that the IRAP is an absolute measure of relational responding, the methodology and theoretical foundation of the IRAP must be outlined. As such, one must describe relational frame theory as the theoretical foundation of the IRAP, before the methodology can be explicated.

Relational Frame Theory

RFT is a theory of language and cognition that was developed based, in part, on research on stimulus equivalence. Stimulus equivalence was empirically demonstrated by Sidman (1971) who discovered that derived or untaught responses emerged when a participant, who could select a picture (A) in the presence of the corresponding spoken word (B), and could speak the word (B) when shown the picture (A); was subsequently taught to select the corresponding written text (C) when presented with the spoken word (B). The derived performances that emerged included symmetry (speaking the correct word (B) in the presence of the text (C)) and transitivity (selecting the correct written text (C) when shown the picture (A), and vice versa ($C \rightarrow A$ and $A \rightarrow C$)). From this, the body of research known as stimulus equivalence emerged (Sidman, 1971; Stewart, McElwee & Ming, 2013). Empirical research revealed that only those with a basic verbal repertoire could pass tests of stimulus equivalence (Barnes-Holmes, Barnes-Holmes, Smeets, Cullinan, & Leader, 2004). Following on from this, behavioural researchers developed RFT as an account of human language; that views stimulus equivalence, and indeed other forms of derived relations such as distinction, opposition, and analogy, as learned behaviours (Barnes-Holmes, Barnes-Holmes, McHugh and Hayes, 2004; Stewart et al., 2013). That is, from an RFT perspective, derived relational responding can be understood as a behavioural operant (Barnes-Holmes et al., 2004; Hayes et al., 2001).

RFT applies many of the findings of stimulus equivalence, but suggests that the relations made in stimulus equivalence that are framed and categorised function as part of a general operant class (Barnes-Holmes et al., 2004). Stimulus equivalence describes the phenomenon whereby when a discrimination in language is learned involving stimuli, further discriminations involving those stimuli may occur in cases whereby the discriminations are not explicitly trained (Barnes-Holmes et al., 2004). Relations made by organisms can generally be seen as nonarbitrary, based on physical properties about the stimulus, and arbitrary, based on nonphysical, abstract factors that the individual associates about a discriminated piece of information (Törneke, 2010). Much research supports the existence of non-arbitrary relations in many species; however arbitrary relations are generally only seen in humans (Hayes et al., 2001).

The IRAP was developed from the RFT assumption that verbally able humans have the ability to derive arbitrary relations among stimuli and events; and that this is a critical feature of language. IRAP researchers were interested in capturing demonstrations of verbal behaviour and examining the relative strength, probability and persistence of relational responding (Hussey, Barnes-Holmes & Barnes-Holmes 2015). The basic approach that was developed to assess verbal relations involved training and testing for laboratory -induced equivalence classes that would most likely conflict with specific pre-existing verbal relations. The prediction was that laboratory-induced classes would not emerge as easily as pre-existing verbal relations, since the lab-induced relations would be in direct competition with the individual's natural verbal relations (Barnes-Holmes, Barnes-Holmes, Stewart & Boles, 2010). This approach provided the conceptual foundation for creating the IRAP.

The Implicit Relational Assessment Procedure (IRAP)

Based on the theoretical framework of RFT, the IRAP is a measure which assesses relational properties between sample and comparison stimuli with a view to examining implicit biases and attitudes through the measurement of reaction times. The associative attribute model (Greenwald et al., 1998) that postulates that highly associated categories should show higher rate of response than low associated categories, as in the IAT, is an assumption made within the IRAP regarding relations and verbal histories (Barnes-Holmes et al., 2011). A basic IRAP might present the sample/label stimuli ‘pleasant’ and ‘unpleasant’, along with positive/pleasant or negative/unpleasant target words (e.g., ‘flower’ or ‘insect’). The sample and target words would be presented onscreen with two relational terms such as ‘true’ and ‘false’ or ‘similar’ and ‘opposite’. The programme typically presents up to four practice blocks and six test blocks. Within block, consistent and inconsistent trials are presented; participants are required to respond to a rule deemed consistent with their assumed relational history, and a rule deemed inconsistent with their assumed relational history (Hughes, Barnes-Holmes & Vahey, 2012). A *consistent* trial in this instance would present the sample stimulus ‘pleasant’ presented with the target stimulus ‘flower’ or ‘unpleasant’ with ‘insect’. An *inconsistent* trial would present ‘pleasant’ with ‘insect’ and ‘unpleasant’ with ‘flower’. The blocks present four different trial-types (e.g., pleasant-positive, pleasant-negative, unpleasant-positive, unpleasant-negative) created by presenting each sample with two sets of target stimuli and two response options (Barnes-Holmes et al., 2006; Barnes-Holmes, Barnes-Holmes et al., 2010). The average difference in response latency between *consistent* and *inconsistent* blocks represents a bias toward finding it easier to respond on consistent relative to inconsistent blocks; and this is thought to expose an implicit attitude or bias (Hussey et al., 2015). Average accuracy scores are recorded across blocks of correct responses relative to the block-rule, however these are not typically the primary datum

analysed; rather latency score typically serve as the primary analysis for the existence of biases.

The basic IRAP methodology includes elements from the IAT, but is derived from prior RFT-based procedures such as the Relational Evaluation Procedure (REP: Cullinan, Barnes & Smeets, 2000). The IRAP has traditionally been applied to assess equivalence classes that were likely to conflict with explicit self-report measures of attitude (Barnes-Holmes et al., 2010); and has provided the scientific community with valuable information regarding implicit attitudes towards various groups including older adults (Cullen et al., 2009), social groups (Barnes-Holmes, Murtagh, Barnes-Holmes, 2010) and children with autism (Kelly & Barnes-Holmes, 2013); and has examined many issues including homo-negativity (Cullen & Barnes-Holmes, 2008), weight bias (Roddy, Stewart, Barnes-Holmes, 2010), gender bias (Murphy, MacCarthiagh & Barnes-Holmes, 2014), and attractiveness bias (Murphy, Hussey, Barnes-Holmes, Kelly, 2015). In many of these studies, comparisons between the IRAP and self-report measures showed that the IRAP had the ability to detect implicit bias that was not revealed in related explicit measures. The Relational Elaboration Coherence model (REC; Barnes-Holmes et al., 2011) aims to explain this type of divergence between implicit and explicit measures of attitudes from an RFT perspective.

The Relational Elaboration Coherence (REC) Model

According to the REC model within RFT, presentation of stimuli within the IRAP may produce brief or immediate relational responses (BIRR's) to stimuli which are likely to be influenced by the verbal and relational history of the individual (Barnes-Holmes, Barnes-Holmes et al., 2010; Hughes et al., 2011). It is suggested that immediate responses to trials within the IRAP should convey implicit relations regarding the stimulus, due to the relationship between verbal and relational history of the individual and BIRRs in response to stimulus presentation (Barnes-Holmes, Barnes-Holmes et al., 2010). The individual is

DEMENTIA & STIGMA IRAP

responding in a manner that adheres to a presented rule, and not based on their own attitude or opinion. The assumption of the IRAP is that presentation of stimuli in a relational network that is consistent with the individual's verbal and relational history would lead to greater ease in response, and faster rate of responding, with inconsistent rules having greater difficulty and larger response time (Barnes-Holmes, Barnes-Holmes et al., 2010). Responding on explicit measures on the other hand, is more careful and deliberate, as individuals are not under strict time constraints, and can consider their responses. The REC model assumes therefore that responses on self-report measures reflect relatively elaborate and coherent relational responding (Barnes-Holmes, Hayes, & Dymond, 2001).

The IRAP effect then, according to the REC model, is produced by BIRRs required of the participant under the time pressures across blocks of trials; while explicit questionnaire measures demonstrate extended and coherent relational networks. In comparing implicit and explicit responses then, if responses on the IRAP (automatic evaluative responses) do not cohere with subsequent relational responding, there will be differences in effects between the IRAP and explicit measures; in that participants are thought to reject their BIRRs if they do not cohere with their more elaborate and extended relational responding (Barnes-Holmes, Barnes-Holmes et al., 2010).

Brief and immediate relational responses are assessed within the IRAP by applying a median response latency criterion and a mean accuracy criterion. These response criteria ensure the validity and reliability of IRAP performances; and as explained by the REC model, allows for examination of implicit biases. Up to 2010, IRAP researchers had typically used an 80% accuracy and a 3,000ms latency criterion; but upon exploring and refining the properties of the methodology, research showed that reducing the practice latency criterion from 3,000 to 2,000ms increased the validity and reliability of the IRAP. Specifically, increased racial stereotyping effects were reported on the IRAP with the reduced latency

(Barnes-Holmes, Murphy, et al., 2010). Since this finding was reported, IRAP studies typically use a 2000ms latency. Barnes-Holmes, Barnes-Holmes et al. (2010) noted however, that latency criteria, as well as accuracy, should be adjusted based on pilot work to suit the stimuli being used or population being assessed. If longer statements as opposed to single words are being presented in the IRAP, or if certain populations process the information at a slower pace, the latency criterion may need to be adjusted to 3,000 ms or more to avoid high attrition rates.

The Current Study

Although implicit measures such as IAT and the IRAP have been used to assess stigma towards mental health (IAT; Peris, Teachman & Nosek, 2008) and older adults (IRAP; Cullen et al., 2009), the area of bias towards people with dementia has not previously been addressed by implicit research, and the extant research literature involves primarily explicit self-report survey measures. While evidence supports a variety of implicit measures, this study attempted to capitalise specifically on the benefits of the IRAP as a non-relative measure of relations in order to measure stigma towards dementia. The current study has four main aims: 1) To develop the IRAP as a measure of implicit dementia stigma; 2) To use the IRAP to examine implicit bias toward dementia (i.e., healthy adults versus adults with dementia) with non-careworker populations versus care-workers' who work with people with dementia ; 3) To examine explicit responses on the DAS, the Fraboni Scale of Ageism-Augmented, the PRISM-PC Dementia Screening Subscale, and the Depression, Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995) for all participants, and also the Maslach Burnout Inventory (MBI; Maslach & Jackson, 1981) and the SEWRD-Q for care-workers; and 4) To compare responses between groups on both explicit and implicit measures. Non-careworker participants were recruited from the general population, and participants were asked to self-exclude if they had any immediate family member with dementia, or if they

DEMENTIA & STIGMA IRAP

informally care for a person with dementia. The care-workers were recruited from care homes in Ireland, and were required to work in a professional capacity with individuals with a diagnosis of dementia.

CHAPTER 2

Experimental Analysis of Dementia Stigma

DEMENTIA & STIGMA IRAP

Research on dementia has shown that stigma continues to be a pertinent issue for people with dementia, their families and the broader community (Batsch & Mittelman, 2012). To date, dementia stigma research has relied on questionnaire and self-report measures, which may be affected by socially desirable responding (Greenwald et al., 2002). Implicit attitude measures can offer an alternative method of assessing attitudes, and these measures have been shown to assess biases not previously accessed by explicit measures (Barnes-Holmes et al., 2006; Barnes-Holmes, Barnes-Holmes et al., 2010). For example, Cullen et al. (2009) used the IRAP to determine whether undergraduate students held implicit ageist attitudes. They found that participants showed negative biases towards older adults that were not reported in explicit measures. The researchers then went on to examine the malleability of the effect by showing pictures of admired and disliked old and young individuals. They found that pro-old exemplars reduced the pro-young IRAP effects and reversed the anti-old effect. This suggested that responses on the IRAP may be affected by information provided or participant knowledge (also see Kelly & Barnes-Holmes, 2015). In relation to stigma more specifically, Peris et al. (2008) developed the IAT as a measure of mental health stigma and examined implicit and explicit attitudes of professionals with mental health training, undergraduates and the general public. Their results showed that compared to those without mental health training, mental health professionals demonstrated more positive implicit and explicit attitudes towards people with mental illness.

The results of both of the studies outlined above suggest that implicit measures can be used to measure stigma towards vulnerable groups in society. The studies also suggest that responses may differ across specific societal groups depending on the information provided to participants, or knowledge or professional experience of that group. The primary aim of the current study was to develop the IRAP as a measure of dementia stigma; in order to contribute implicit data to the existing body of literature using self-report measures, and to

enhance the understanding of stigma towards people with dementia. The research also examined whether responding would differ for non-careworkers populations versus those with professional experience (care-workers who work with people with dementia). Implicit and explicit responses will be assessed across groups, and responses across measures will be compared. I hypothesise based on prior research that 1) non-careworker populations will show more negative biases towards people with dementia compared to care-workers, 2) experience of care-workers will impact their implicit biases; 3) responses on the implicit measure will diverge from those on the explicit measure of dementia stigma bias; and 4) explicit measures of depression, anxiety, stress, burnout, and job satisfaction will correlate with implicit negative biases.

Methods

Participants

Forty-nine individuals participated in the experiment, consisting of 14 males and 35 females. Participants were required to meet pass criteria on the IRAP in order for their data to be included in the analysis (see procedure). In total, data from nine participants were excluded from the analysis. This included data from three non-careworkers and six careworkers who did not fulfil the IRAP pass criteria. The final sample for analysis therefore was $n=23$ non-careworkers (12 males and 11 females; mean age = 21.5; age range = 19-25), and $n=17$ carers (2 males and 15 females; mean age = 26.88 ; age range = 19-51).

Care workers were recruited from three sites in the South of Ireland, with the aid of the Alzheimers Society and other professional institutes through contacting representatives of these organisations, and presenting the information sheet (see appendix 2). The years of experience working with people with dementia ranged from 1 to 26 years, (mean = 6.47, standard deviation = 8.1) and all had received dementia-specific training. Non-careworkers

included students from Maynooth University and individuals from local communities of Kildare and Naas. Potential participants were not recruited if they had an immediate family member with dementia; or provided informal unpaid care to a person with dementia.

Experimental Design

The research was conceptualised as a mixed 2 x 4 factorial design. The between participant independent variable was Group, with two levels including careworkers and non-careworkers. The within-participant repeated measures independent variable was IRAP trial-type, with four levels including *dementia-positive*; *dementia-negative*; *healthy-positive*; *healthy-negative*. The dependent variable was participants' IRAP data, or *D*-scores (see below for details on calculation).

Ethical Considerations

The experiment was approved by the University Ethics Committee to be conducted as a postgraduate research project in Maynooth University. As such, the research was conducted in line with the rules and practices of the Maynooth University ethical guidelines. Dementia is a topic which may be considered socially sensitive. Individuals who were taking part in the experiment could have found the issues being analysed upsetting on a personal level, due to the potential of individuals being impacted by dementia within their personal life. For this reason, in consent forms and information sheets (see appendices 1 and 2) participants were encouraged not to take part if they felt they would find the topic distressing. Participants were informed that if they felt in any way distressed during the experiment, they were free to withdraw from participation at any time. Participants may have also felt uncomfortable with disclosing personal information within the questionnaires, and care-workers may have felt that the additional questionnaires related to working in the area of dementia care were of a sensitive nature. Participants were therefore made aware of the anonymity of their data.

Confidentiality and anonymity were assured by taking measures so that only the researcher and academic supervisors had access to participant data. Each participant was assigned a participant code and number which was correspondent to their data. This participant number was assigned to data related to both the IRAP and explicit measures; and was used in the analysis of the data. Protection and storage of data will follow the guidelines of the Maynooth University Data Protection Policy, which is regulated in accordance with the Data Protection Act of 1998 and the Data Protection (Amendment) Act of 2003. Information sheets that informed the participants of the topic and nature of the study in accessible language were provided to potential participants at least 24 hours in advance of their scheduled participation. For care-workers, an information sheet was provided to the institution as well as contact information of the researcher. Informed consent was gathered by means of a signed consent form (See appendix 2). Participants were appropriately debriefed subsequently by the primary researcher.

Apparatus and Materials

The research was conducted in either the place of employment of care workers, quiet laboratory cubicles at Maynooth University, or in a quiet room in participants' homes, free from distractions. In each case, participants were seated at a table in a quiet room free from any distractions. The IRAP programme was presented on a standard Dell laptop; and the IRAP software controlled all aspects of the programme presentation (IRAP software is available upon formal request to Prof. Dermot Barnes-Holmes: Dermot.Barnes-Holmes@ugent.be). The explicit measures were administered after the IRAP was completed.

The IRAP. The IRAP programme contained two sample stimuli, 12 target stimuli and two response options (see Table 1). The two sample stimuli were “healthy adult” and “adult with dementia”. The target stimuli included positive responses (“capable”, “able”,

DEMENTIA & STIGMA IRAP

“independent”, “pleasant”, “positive” and “enjoyable”); and negative responses (“incompetent”, “helpless”, “unable”, “difficult”, “unpleasant”, and “irritating”). Response options were “true” and “false”. The IRAP presented specific rules for participants to follow. The rules were deemed either consistent or inconsistent based on findings of prior research on dementia stigma (e.g., Burgener & Berger, 2008; Scholl & Sabat, 2008; Werner, 2000). The consistent rule stated that “Healthy adults are positive and adults with dementia are negative”; and the inconsistent rule stated that “Healthy adults are negative and adults with dementia are positive”. The presentation of the consistent rule versus the inconsistent rule first was counterbalanced across participants. The IRAP presented the sample stimuli at the top of the screen, the positive and negative sample stimuli in the centre of the screen; and the response options at the bottom left and right of the screen (see Figure 1).

Table 1

Stimulus Arrangements and Word Groups Presented by the IRAP

Sample 1	Sample 2
Capable Able Independent Pleasant Positive Enjoyable	Incompetent Unable Helpless Unpleasant Difficult Irritating
Targets deemed consistent with Sample 1 Healthy Adult	Targets deemed consistent with Sample 2 Adult with Dementia
Response Option 1 True	Response Option 2 False

Dementia Attitudes Scale (DAS). The DAS (See appendix 3) is a 46 point scale which assesses attitudes towards dementia across two factors; dementia knowledge and social comfort. Responses to statements are provided on a likert scale ranging from “strongly agree” to “strongly disagree”. This questionnaire was developed by O’Connor and McFadden (2008) and is developed from existing validated cognitive models of attitudes (Breckler, 1984). On

the DAS, higher scores for both scales indicate indicate higher levels of both comfort and knowledge. The questionnaire was developed through psychometric testing of qualitative information gathered from focus groups about dementia and attitudes towards dementia. It is suggested that of the 46-item scale, a third of questions assess the cognitive component of attitudes (i.e., “I am not very familiar with dementia”), a third reflect the affective component of attitudes (i.e., “I feel relaxed around people with ADRD”) and a third reflect the behavioural aspect (i.e., “I would avoid an agitated person with ADRD”). Research has suggested that the DAS is a valid and reliable scale in analysing attitudes towards dementia (O’Connor & McFadden, 2008).

Fraboni Scale of Ageism-augmented. The Fraboni Scale of Ageism (see Appendix 4) assesses biases towards ageing populations through analysis of levels of avoidance or separation towards ageing populations (Fraboni, Salstone & Hughes, 1990). An augmented version of this questionnaire was applied in order to assess rates of avoidance of individuals with dementia, as is designed by Phillipson (2012). This is a 31 point questionnaire which provides statements with a scale of 5 optional responses ranging from “strongly agree” to “strongly disagree”. On this questionnaire, scales related to avoidance which demonstrated higher responses indicated a higher rate of avoidance, whereas high responses for general dementia attitudes indicates more positive biases towards dementia.

PRISM-PC (Perceptions Regarding Investigational Screening for Memory in Primary Care Dementia Screening Subscale): This is a 39 item questionnaire (see appendix 5) which assesses bias towards dementia by requiring participants to report how they would respond to a diagnosis of dementia, based on provided statements. Higher responses on this questionnaire for knowledge, acceptance and benefits scales indicated more positive biases towards dementia, while higher responses for the stigma, suffering and independence scales indicated more negative biases towards dementia. The PRISM-PC was

originally developed by Boustani et al (2008) and augmented to analyse perceptions regarding investigational screening (Phillipson, 2012). This questionnaire is highly applicable in assessing identification with individuals with dementia, and how diagnosis may lead to negative emotional responding. The PRISM-PC assesses biases based on two scales: (1) the acceptance scale, and (2) the perceived harms and benefits scale. The acceptance scale has two underlying constructs (knowledge of dementia-screening and being tested for dementia), and the perceived harm and benefits scale has four underlying concepts (benefits, screening, stigma, and negative impacts of screening on dementia; see Boustani et al., 2008). Seven questions from the initial PRISM-PC questionnaire were omitted in the current study. Five of these included questions which function to gain information about individuals' personal experience dealing with persons with dementia. These were omitted due to the fact that this information was collected prior to beginning the experiment. Furthermore two open-ended questions related to perceived harm and benefits of dementia screening were omitted as they could not be factored into the two scales being measured.

Depression Anxiety Stress Scale (DASS). This questionnaire (see Appendix 6) consists of 42 statements which analyse how the participant was feeling in the week prior to completing the experiment. Higher scores indicated higher levels of depression, anxiety and stress. The test assesses levels of low mood, anxiety and stress. This test has been suggested to possess a strong internal validity (Lovibond & Lovibond, 1995). The primary purpose of this measure within the current experiment was to assess correlations between reported rates of depression, stress and anxiety, and reported attitudes towards dementia, as assessed by the other questionnaires. As participants were reporting on topics such as avoidance of individuals with dementia, and anxiety surrounding screening for dementia, the DASS was applied as a control in order to assess whether the participant's mood influenced responding.

Furthermore the DASS was applied to assess the mood of care-workers, in relation to their reports of burnout and experience with their job.

Maslach Burnout Inventory (MBI). The MBI assesses professional burnout in three dimensions; emotional exhaustion, depersonalisation, and personal accomplishment (Maslach & Jackson, 1981; see Appendix 7). The MBI has been consistently assessed and deemed to be valid and reliable in assessing professional burnout (Taris, Schreurs, & Schaufeli, 1999). This questionnaire consists of 22 statements that individuals must respond to on a 6-point scale in level of agreement or disagreement. Higher responses for depersonalisation and emotional exhaustion scales indicated higher rates of burnout, whereas higher responses for the personal accomplishment indicated lower rates of burnout.

Staff Experience of Working with Residents with Dementia-Questionnaire (SEWRD-Q). This is a 21 item questionnaire (see Appendix 8) which provides participants with statements about their work which participants agree to or disagree to on a 4-point scale (Åström et al., 1991). Higher responses to all scales on this questionnaire indicated higher rates of job satisfaction. It attempts to assess staff experience of working with the elderly under six categories; satisfaction, the care organisation, one's own expectations, patient contact, expectation of others, and environment. This questionnaire has been effectively applied across research and has been suggested to possess validity as an assessment of attitudes of dementia care workers towards their occupation (Zimmerman et al., 2005). This questionnaire was applied along with the Maslach Burnout Inventory to assess topics such as satisfaction with the organisation and work environment, which were not assessed by the Maslach Burnout Inventory (research tends to show many of the issues that lead to staff dissatisfaction in nursing homes may not directly relate to the work with the residents itself, and can be more strongly related to industrial and work-environment issues (Aiken et al., 2012).

Procedure

The IRAP. The IRAP computerised task was administered to all participants. The sample stimulus was presented at the top of the screen (e.g., Adult with Dementia or Healthy Adult); one of the target stimuli were presented below this (e.g., incompetent or independent), with response options “true” and “false” presented at the left and right of the screen (fixed right-left locations). Participants were required to choose one of these response options by pressing the “d” key for the option on the left and the “k” key for the option on the right (see Figure 1). Correct and incorrect responses were dictated by whether the correct pairing of target and label stimuli was made in relation to the consistent or inconsistent rule. Correct responses can be operationalised as follows; for the consistent rule “Healthy Adults are positive and Adults with Dementia are Negative”, responses to a “Healthy Adult” label with a positive response (see Appendix 3) were consistent, meaning that selecting “true” would be a correct response. If an “Adults with Dementia” label was presented with this positive target stimulus, this would be incorrect based on the rule, meaning that “false” would be the correct response. Similarly if “Healthy Adults” was paired with a negative target stimulus, the correct response would be “false”, as under the consistent rule, healthy adults are positive. For the inconsistent block rule, “Healthy Adults are negative and Adults with Dementia are Positive”, presentation followed the same format, with opposite criteria necessary for correct responses. In this case, all pairings of “Healthy Adults” with negative words were considered “true”, and all pairings of “Adults with Dementia” with positive words were considered true, with the opposite pairings of each being considered false.

The methodology of this IRAP was applied in line with guidelines outlined by Barnes-Holmes et al (2010). When a correct response was emitted by the participant (determined by the rule for that block of trials), the screen was blank for a brief period of 400 milliseconds before the next trial was presented. If the stimuli were incorrectly responded to,

a red X appeared below the target stimulus. The participant was required to select the correct response in order to clear the red X. In addition to the 'X' feedback for incorrect responses, a red exclamation point ("!") would appear at the bottom of the screen during test blocks when participants response time exceeded 2000ms. Average response times were required to be below 2000ms in each block of trials. The participant's average latency was presented on-screen upon completion of each block of trials. Instructions were provided to participants prior to beginning the experiment that they should attempt to avoid the "!"; and so avoidance of the exclamation point acted as a behavioural control on speed of responding.

The IRAP presented blocks of 24 trials. Trials were presented quasi-randomly within each block. Each of the 12 positive and negative sample stimuli appeared once with the two target stimuli ("Healthy Adults" and "Adults with Dementia"). The IRAP commenced with blocks of practice trials designed to allow participants to reach a performance criterion prior to beginning the test phase of the IRAP. When the 24 trials of the first practice block were completed, information including percentage of correct responses and median latency were presented to participants. The next block of practice trials required the opposite pattern of responding (as explained above). Participants completed a maximum of four sets of practice blocks (eight blocks in total). Once practice criteria were met on each of the two blocks of trials (normally >80% accuracy and <=2000 ms), the participant moved straight into test blocks. If practice criteria were not met after four attempts, they did not complete the test IRAP, and were thanked and excused from the experiment. For the six test blocks, participants were informed that it was a test at the beginning of each block; and there were no performance criteria. Once the test phase of the IRAP commenced, participants continued until all six blocks were completed. If performance on a consistent and inconsistent block fell below 80% accuracy or exceeded 2000 ms, the data for that participant were discarded.

Explicit measures. Upon completion of the IRAP, participants were required to complete a range of explicit measures. The care-workers completed the DAS, the Fraboni Scale of Ageism- augmented, the PRISM-PC Dementia Screening Subscale, the DASS, the MBI, and the SEWRD-Q. The non-careworker completed the DAS, the the Fraboni Scale of Ageism- augmented, the PRISM-PC Dementia Screening Subscale, and the DASS. Upon completion of the study, participants were provided with debriefing forms and thanked for their participation.

Intervention for High Fail Rates

When data collection began, training consisted of providing participants with a brief explanation on what the task required in relation the rule and responding true or false; and the practice blocks of the IRAP. The experimenter would stay with the participant for the initial two practice blocks to ensure the participant was familiar with both the consistent and inconsistent forms of the trial block. Following this, participants would generally be left to complete the remainder of the practice blocks and proceed to the test blocks in the experimental lab by themselves. After running 34 participants however, there was a noticeably high fail rate of 40% across participants. This meant that only 60% of participants were meeting pass criteria of 80% accuracy and 2000ms latency.

Practice. An intervention was therefore put in place for *all participants* to increase the level of training and attempt to reduce the fail rate of participants. Participants were provided with visual cues on a piece of paper which explained how rules and trials would appear on-screen during the IRAP. The rules were shown to the participants and they were asked how they would respond to the trials (presented on the page), based on the rule that had been given. Essentially, this functioned analogously to the practice blocks on the IRAP, with the sole difference being the removal of the computer in the initial training stage. Participants then went on to complete the practice blocks and test blocks of the IRAP as usual. This aimed

to familiarise participants with the presentation of the IRAP and the words used within the IRAP.

Results

Overview of Data Analysis

The analysis of implicit (IRAP) and explicit (questionnaires) measures included the use of Analysis of Variance (ANOVAs), t-tests, and correlational analysis. Mixed within between analyses of variance were used to analyse IRAP data, with follow-up one sample t-tests used to examine individual effects on the IRAP. The data applied in these analyses were the D-IRAP scores across the four different trial types. Pearson's correlations explored relationships between implicit and explicit measures. Analysis included IRAP data comparing the two groups, careworkers and non-careworkers.

IRAP Data

The IRAP data subjected to analysis was participants' response latencies across IRAP trial-blocks, defined as time in milliseconds between the onset of an IRAP trial and a correct response. The response latency data were transformed into *D*-IRAP scores using an adaptation of the Greenwald et al. (2003) *D* algorithm (Barnes-Holmes, Murtagh, Barnes-Holmes, & Stewart, 2010; Cullen & Barnes-Holmes, 2008). *D*-IRAP scores are calculated using the following steps: (1) only response latency data from test blocks were included; (2) latencies above 10,000 ms were not included; (3) if participants' data contained more than 10% of test block trials with latencies less than 300 ms, they were removed; (4) 12 standard deviations for the four trial types were calculated: four for the response latencies from test blocks 1 and 2, four for the response latencies from test blocks 3 and 4, and four for the response latencies from test blocks 5 and 6; (5) 24 mean latencies were calculated for the four trial-types in each test block; (6) difference scores for each of the four trial types were

calculated for each pair of test blocks by subtracting the mean latency of the healthy adults-positive block from the mean latency of the corresponding dementia-positive block; (7) each difference score was then divided by its corresponding standard deviation from step 4, yielding 12 *D*-IRAP scores, one score for each trial type for each pair of test blocks; (8) four overall trial-type *D*-IRAP scores were calculated by averaging the three scores for each trial-type across the three pairs of test blocks. This transformation of data yields positive *D*-scores that indicate a negative bias towards people with dementia and a positive bias towards healthy adults; and yields negative *D*-scores that indicate a positive bias towards people with dementia and a negative bias towards healthy adults.

IRAP Analysis

The IRAP analysis was performed on all participants who had met pass criteria. This consisted of a total of 40 participants, with 14 males and 26 females; $n = 23$ non-careworkers, and $n = 17$ care-workers. The four overall mean *D*-IRAP scores for each trial-type are presented in Figure 1. The trial types analysed were; (1) *healthy adults - positive*, (2) *healthy adults - negative*, (3) *adults with dementia - positive*, and (4) *adults with dementia - negative*. The *D*-IRAP score responses were interpreted as follows; for the “*healthy - positive*” trial-type, a positive score would indicate a bias towards healthy adults as positive. For the “*healthy - negative*” trial-type, a positive score would indicate a bias towards healthy adults as not-negative. For the “*dementia - positive*” trial-type, a positive score would indicate a bias towards adults with dementia as not-positive. For the “*dementia - negative*” trial-type, a positive score would indicate adults with dementia are negative. Across the four trial-types, the groups responded with overall mean *D*-IRAP scores of 0.4217, 0.2338, 0.058, and 0.1402. This shows a healthy – positive; healthy – not negative; dementia – not positive; dementia – negative pattern of responding.

One-sample t-tests were conducted to determine if the *D*-IRAP scores for each trial-type differed significantly from zero across both groups. Bonferroni adjustments for multiple comparisons were conducted which indicated an adjusted alpha of $\alpha = .0125$. For the non-careworker group, there was a significant difference from zero identified for ‘*healthy – positive*’ ($M = .498$, $SD = .487$; $t(22) = 4.907$, $p < .001$); and ‘*healthy – negative*’ ($M = .317$, $SD = .373$; $t(22) = 4.09$, $p < .001$). The ‘*dementia – positive*’ ($M = .227$, $SD = .459$; $t(22) = 2.37$, $p = .027$); and ‘*dementia – negative*’ ($M = .207$, $SD = .427$; $t(22) = 2.33$, $p = .030$) were not statistically significantly different from zero. For the careworkers, there was a significant difference from zero identified for ‘*healthy – positive*’ ($M = .318$, $SD = .305$; $t(16) = 4.294$, $p = .001$); but no significant difference from zero for any of the remaining trial-types (‘*healthy – negative*’ $p = .252$; ‘*dementia – positive*’, $p = .091$; ‘*dementia – negative*’, $p = .592$).

The four *D*-IRAP trial-type scores were entered into a 2 x 4 mixed repeated measures analysis of variance (ANOVA) with group as the between-participant variable and IRAP trial-type as the within-participant variable. Bonferroni adjustments for multiple comparisons were conducted which indicated an adjusted alpha level of $\alpha = .0167$. There was a significant within-subjects effect for trial type, $F(3, 36) = 10.376$, $p < .001$. There was no significant interaction effect between trial type and group $F(3, 36) = 1.41$, $p = .254$. The main effect for group (i.e., careworkers vs non-careworkers) was not significant, $F(1, 38) = 5.512$, $p = .024$, Wilk’s Lambda = .254, partial eta squared = .127.

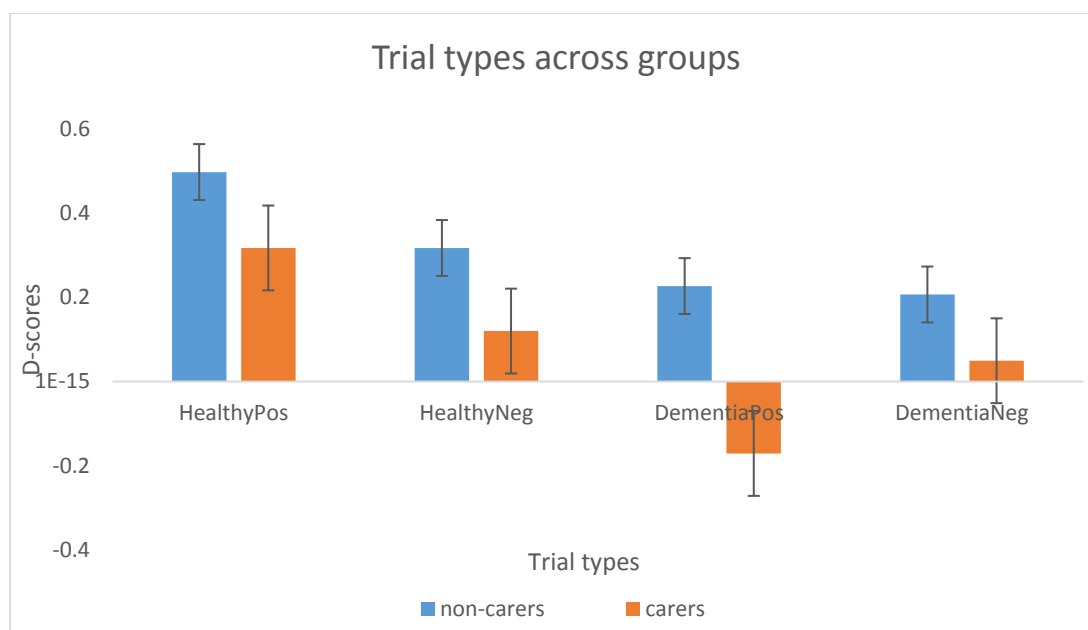


Figure 1: Comparison of trial-type D-IRAP scores across the two groups. For non-careworkers, the graph shows a healthy-positive (not-negative), dementia-not-positive (dementia-negative) pattern of responding. Care-workers show healthy-positive (not-negative) and dementia-positive (and dementia-negative) responses..

Four follow-up between-groups ANOVAs examined differences between the groups across the four trial-types individually. Bonferroni adjustments for multiple comparisons were conducted which indicated an adjusted alpha level of $\alpha = .0125$. For the ‘healthy adults-positive’ trial-type, there was no statistically significant difference between groups, $F(1, 38) = 1.208, p = .187$. For the ‘healthy adults-negative’ trial type, there was no statistically significant difference between groups, $F(1, 38) = 2.486, p = .123$. For the ‘dementia-positive’ trial type, there was a statistically significant difference between groups, $F(1, 38) = 8.285, p = .007$. There was no statistically significant difference between groups for the ‘dementia-negative’ trial type, $F(1, 38) = 1.476, p = .232$.

Two follow-up within-group ANOVAs were conducted for both groups to compare all trial-types within-groups. . Bonferroni adjustments for multiple comparisons were conducted which indicated an adjusted alpha level of $\alpha = .025$. For the non-careworker group,

there was a significant effect for trial type, Wilks Lambda = .602, $F(3, 20) = 4.40$, $p = .016$, partial eta squared = .398. Pairwise comparison using Bonferroni adjustments for multiple comparisons indicated a significant difference between the '*healthy-positive*' trial type and '*dementia-negative*' trial type, $p = .010$. There were no significant differences between any other trial types. For carers, there was a significant effect for trial type, Wilks Lambda = .391, $F(3, 14) = 7.27$, $p = .004$, partial eta squared = .271, with differences shown between the *healthy-positive* trial type and *dementia-positive* trial type, $p = .002$ only.

Overall, the IRAP data demonstrated that non-careworkers held significant healthy-positive (not-negative) biases but dementia-negative (not-positive) biases; while care-workers held significant healthy-positive (not negative) biases but weak dementia-positive and dementia-negative biases. There were no significant differences between groups. At the level of the individual trial-type, there was a significant between group differences between careworkers and non-careworkers for the '*dementia – positive*' trial-type. This showed that care-workers have a more positive bias towards people with dementia compared to non-careworkers. Within group analyses identified that in both care-workers and non-careworkers there were significant differences within groups for the four trial types

Explicit Measures Analysis

Between-groups differences in questionnaire scales for the DAS, PRISM-PC, Fraboni Scale of Ageism, and DASS scales were analysed using analysis of variance tests. No between groups analysis could be performed on the SEWRD-Q or MBI questionnaires, as they were only performed on one group, the carer group.

A mixed repeated measures ANOVA was conducted to assess the difference between groups on scores in the DAS scales, comfort ($M = 4.11$, $SD = 1.05$) and knowledge ($M = 2.845$, $SD = .708$). The Bonferroni corrected alpha level for this test was $\alpha = .0167$. There

DEMENTIA & STIGMA IRAP

was no significant interaction effect between group and DAS scores, Wilks' Lambda = .993, $F(1, 38) = 1.00$, $p = .997$. There was no significant main effect for group, Wilks' Lambda = .987, $F(1, 38) = 5.821$, $p = .021$. Pairwise comparison using bonferroni corrections for multiple comparisons between DAS scales indicated these scales did not differ significantly from one another, $p = .617$. Analysis of effects between groups for the DAS indicated the two groups did not differ significantly in responding to the DAS, Wilks Lambda = .993, $F(1, 38) = 5.821$, $p = .021$. Pairwise comparisons between DAS scales indicated these scales did not differ significantly from one another.

A mixed repeated measures ANOVA was conducted to assess the difference between groups on scores in the six PRISM scales, knowledge ($M = 4.11$, $SD = 1.05$), acceptance ($M = 3.47$, $SD = 1.06$), benefits ($M = 4.36$, $SD = 0.525$), stigma ($M = 2.85$, $SD = .714$), suffering ($M = 3.96$, $SD = .622$), and independence ($M = 3.17$, $SD = .71$). The Bonferroni corrected alpha for this analysis was $\alpha = .0167$. There was no significant interaction effect between group and PRISM scores, Wilks' Lambda = .194, $F(5, 33) = 1.017$, $p = .423$. There was no significant main effect for group on PRISM scores, Wilks' Lambda = .194, $F(1, 37) = 1.970$, $p = .169$.

A mixed repeated measures ANOVA was conducted to assess the difference between groups on scores in the three DASS scales, depression ($M = 3.15$, $SD = .745$), anxiety ($M = 3.20$, $SD = .748$), and stress ($M = 2.97$, $SD = .731$). The Bonferroni corrected alpha for this analysis was $\alpha = .0167$. There was no significant interaction effect between group and DASS scores, Wilks' Lambda = .958, $F(2, 37) = .825$, $p = .450$. There was no significant main effect for group on DASS scores, $F(1, 38) = 1.50$, $p = .228$. Pairwise comparisons using Bonferroni corrections for multiple comparisons indicated no significant differences between depression and stress, $p = .022$, or between anxiety and stress, $p = .029$.

Correlation analysis

The relationship between the four IRAP trial types and the twenty individual questionnaire scales was investigated using Pearson’s product-moment correlation coefficient. The Bonferroni corrected alpha for this analysis was $\alpha = .000625$. There were no significant correlations identified between the IRAP trial types and any of the 20 questionnaire scales at the corrected alpha level. As Type II error rates may be high for analyses with large numbers of inter-correlations, analysis was also performed at $\alpha = .05$ for comparative purposes.

Table 2

Correlation matrix comparing whether the scales in questionnaires used correlated with any of the four D

<u>Explicit measures</u>	<u>Healthy</u>	<u>Healthy</u>	<u>Dementia</u>	<u>Dementia</u>
	<u>Positive</u>	<u>Negative</u>	<u>Positive</u>	<u>Negative</u>
DAScomfort	-0.123	-0.184	-0.212	-0.192
DASknowledge	-0.085	-0.204	-0.203	-0.103
PRISMknowledge1	0.184	0.053	0.046	-0.086
PRISMacceptance1	.325*	-0.075	-0.021	0.212
PRISMbenefits1	0.151	-0.205	-0.033	-0.135
PRISMstigma1	0.116	-0.151	-0.137	0.112
PRISMstuffering1	0.203	-0.191	-0.045	0.016
PRISMindependence1	0.147	-0.155	0.144	.390*
MBIemotionalexhaustion1	0.477	-0.409	-0.353	0.377
MBIpersonalaccomplishment1	0.201	-0.251	0.038	0.067
MBIdepersonalisation1	-0.005	-0.157	-.546*	0.395
SRDQfeedback1	-0.264	0.225	-0.18	0.315
SRDQorganisations1	-0.402	-0.044	-0.325	-0.317
SRDQownexpectations1	-0.034	0.076	-0.381	-0.168
SRDQpatientcontact1	-0.411	0.29	0.069	0.256
SRDQothersexpectations1	-.540*	-0.197	-0.405	-0.442
SRDQenvironment1	0.072	0.011	0.022	0.028
DASSdepression	-0.103	0.011	-0.015	-0.102
DASSanxiety	-0.093	-0.017	0.05	-0.147
DASSstress	-0.059	0.043	0.072	-0.148

* Correlation is significant at the 0.05 level (2-tailed).

DEMENTIA & STIGMA IRAP

** Correlation is significant at the 0.000625 level (2-tailed).

The total scale scores from each of the questionnaires were analysed in order to assess any significant correlations between questionnaires. The Bonferroni corrected alpha for this analysis was $\alpha = .0025$. It was demonstrated here that there were no significant correlations between any of the questionnaires at the corrected alpha level.

Table 3

Correlations examining relationships between total scale scores of questionnaires

	<u>DASStotal</u>	<u>PRISMtotal</u>	<u>MBItotal</u>	<u>SWRDtotal</u>	<u>DASStotal</u>
<u>DASStotal</u>	1	0.074	0.056	.837**	-0.1
<u>PRISMtotal</u>	0.074	1	.538*	0.171	-0.165
<u>MBItotal</u>	0.056	.538*	1	0.372	0.104
<u>SWRDtotal</u>	.837**	0.171	0.372	1	0.366
<u>DASStotal</u>	-0.1	-0.165	0.104	0.366	1

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.0025 level (2-tailed).

Summary of Results

The IRAP data suggested that there was an overall bias identified, with both groups demonstrating *healthy - positive* biases, and differences occurring in relation to *healthy - negative* biases. Despite this, there was no overall significant between-groups difference; and as such group differences did not have an impact on responding to the IRAP. While there was a moderately large effect size (partial eta squared) which may have suggested a trend towards significance at the adjusted alpha, overall adjusted alpha levels yielded no significant results between groups. Three of the individual trial-types did not demonstrate significant between groups' differences. There was a significant between groups difference for the *dementia – positive* trial type. Analysis of individual groups suggested that non-careworkers' responses

DEMENTIA & STIGMA IRAP

were negative (and not positive) towards people with dementia but positive (and not negative) towards healthy adults. Care workers showed effects that were both positive and negative towards people with dementia (although greater effects for positive compared to negative), and positive (and not negative) towards healthy adults.

On all three explicit measures of stigma, there were no differences found between the groups, a result in line with IRAP data. Correlational analysis did not yield significant correlations between IRAP and factors in the questionnaires, indicating there was not a strong relationship between individuals' self-reported attitudes towards dementia, and IRAP results.

Chapter 3

Discussion

The current research sought to develop the IRAP as a measure of dementia stigma; and to determine whether responses on the IRAP would show an implicit negative bias towards adults with dementia and/or an implicit positive bias towards healthy adults, and the nature of any bias that existed. The research further sought to determine whether the variable of whether or not individuals had professional experience with dementia had an impact on potential dementia stigma by assessing attitudes of both non-careworkers populations and care-workers, and assessing whether differences existed between these groups that could be statistically meaningful. Complimentary to this, the research aimed to further examine stigma through the application of explicit measures, with a view to ascertaining level of bias but also potential causes that may underlie biases as measured by the IRAP and self-report questionnaires. The current chapter is divided as follows: Firstly, the general findings of the experiment will be discussed and interpreted in the context of prior research. Conceptual and procedural issues within the current study related to the findings and the length to which findings can be interpreted as meaningful are discussed. Broader conceptual issues and considerations for future research, as well as limitations of this research programme will also be discussed.

Study Aims and Results

The initial aim of this study was to assess whether the IRAP could be used to investigate implicit biases towards adults with dementia and healthy adults. The primary research questions aimed to examine whether: implicit stigma towards people with dementia exists; and whether knowledge and experience impact any biases. The researcher hypothesised that overall, there would be a healthy-adult-positive and adult-with-dementia-negative bias shown. Specifically, non-careworker populations would show more negative biases towards people with dementia compared to care-workers. Care-worker biases were expected to be more dementia positive due to experience and training. It was also

hypothesised that responses on the implicit measure would diverge from the explicit measures; and that measures of depression, anxiety, stress, burnout, and job satisfaction would correlate with explicit and implicit negative biases. The area of dementia stigma is a topic that has not been previously examined within published IRAP research, and has been notably scarce among implicit research in general. This research therefore was largely exploratory.

The findings of the current study suggested an overall positive implicit bias towards healthy adults and differences between groups in relation to biases towards people with dementia, as shown by individual *D*-IRAP effects across trial-types. Despite this, there were no overall significant differences between groups. Within participant analyses indicated that there were significant differences between the four trial-types, however the group variable did not influence this effect. As such, the IRAP data demonstrated that in the context of careworkers versus non-careworkers, experience with those with dementia may not significantly influence levels of bias. Specifically, whether one had experience with those with dementia or not did not appear to impact IRAP responses. This is consistent with existing literature; Kelly and Barnes-Holmes (2013) did not identify differences in IRAP responses between ABA tutors and normal teachers towards children with autism. Therefore in their study, whether or not one worked in a professional capacity with those with autism did not impact IRAP responses (Kelly & Barnes-Holmes, 2013). Hein, Grumm and Fingerle (2011) found similar results whereby exposure to individuals with disabilities did not produce differences in IAT responses to disability bias. As such, current findings may be supported in suggesting that professional exposure to dementia may not significantly change one's implicit bias towards that population, relative to non-careworker populations. Despite the overall lack of difference between groups, significant differences between groups were identified in individual trial types.

Results demonstrated between-group's differences on one specific trial type; the *dementia-positive* trial type. This result can be interpreted in the context of research studies examining the existence of stigma towards individuals with dementia (Batsch & Mittelman, 2012; Peris et al., 2008; Cheng et al., 2011). Research has suggested members of the general public tend to possess negative attitudes towards those with dementia (McParland et al., 2012), which have been characterised as associations about those with dementia as infantilised (Jorm, 2000), lacking awareness (Clare, 2003), and potentially dangerous (Corrigan et al., 2000). This experiment was the first experiment to use the IRAP as an implicit measure of stigma towards people with dementia, and while individual trial type responses may support the finding that people possess generally negative attitudes towards those with dementia; as group differences were not significant overall, one must be highly conservative when analysing the breadth to which differences in trial-type responses may be interpreted as meaningful. Analysis within groups found that both non-careworker populations and care-workers showed positive biases towards healthy adults, although these were stronger among non-careworkers. Therefore the only significant differences between groups on trial-type was in relation to the *dementia-positive* trial type, whereby careworkers responded to suggest dementia is positive, whereas non-careworkers responded to suggest dementia is not positive.

The finding related to the '*dementia-positive*' trial-type prompts a more detailed discussion of whether dementia experience and training influenced stigma towards dementia. Prior research using explicit measures has shown that people who worked in a professional capacity with people with dementia, and who had more experience and training, showed less negative attitudes towards people with dementia (Cheng et al. 2011; Moyle et al., 2011; Richardson et al., 2002). Care-workers were reported to possess positive explicit attitudes towards those within their care and towards those with dementia in general (Kada et al.,

2009; Moyle et al., 2011). These findings are consistent with those reported on explicit questionnaires and the dementia-positive trial-type in this study as care-workers were significantly more dementia-positive than the other two groups. Generally, research shows that education, knowledge and training has a positive impact on implicit attitudes towards stigmatised groups. Peris et al. (2008) reported that those who have mental health training tend to possess more positive implicit and explicit attitudes towards those with mental health issues; while in IRAP research, Cullen et al. (2009) reported that implicit attitudes were malleable to information provided prior to engaging in the IRAP task. Taken together with the results of the experiment, this reiterates the necessity of education and training in addressing issues related to stigma in the general population.

The fact that the care-workers in this study were required to be currently working in a professional capacity with those with dementia, may have been an influencing variable on the more positive dementia biases and lower stigma. If job dissatisfaction is a primary motivator for staff turnover, as research suggests (Lerner et al., 2014), then it is reasonable to postulate that only including individuals who are currently working with individuals with dementia may produce more positive responses towards dementia, as opposed to individuals who had ceased working within the area. Future research may benefit from analysing implicit attitudes of those working within the area versus those who had recently ceased working within the area, in order to assess using implicit measures whether stigma towards dementia may influence employee turnover.

Although care-workers' attitudes were positive towards dementia in one regard, the IRAP also identified a weak negative bias. That is, the IRAP may have offered additional information not accessed by the questionnaires. This suggests the benefits of using a measure that assess bi-directional relations and suggests that addressing stigma may require more than education and training. One factor that mediates professional's attitudes within existing

literature tends to focus around staff dissatisfaction, and burnout. Research has shown generally high levels of job dissatisfaction among care-workers in nursing homes (McGilton et al., 2014; Rodney, 2000). This is consistent across attitude research with mental health professionals. The nursing home industry is one that suffers from a notably high rate of staff turnover (Banaszak-Holl & Hines, 1996; Thomas, Mor, Tyler, & Hyer, 2013). While implicit tests have not generally analysed attitudes towards dementia, IRAP research has been applied in the past to assess professionals working in a care capacity with children with autism, and has demonstrated that teachers with more negative biases towards individuals with autism reported higher rates of professional burnout (Kelly & Barnes-Holmes, 2013). In the current study, care-workers demonstrated positive responses on the *dementia-positive* trial-type. Interestingly, this suggests that lower levels of burnout were related to less dementia stigma; and shows that care-workers should not only be well-educated about dementia, but measures should also be put in place to ensure job satisfaction as less burnout.

Results comparing responses between the careworkers and non-careworkers on the explicit measures demonstrated that there were no significant between-groups differences across scales. The care-workers' mean scores were higher on the DAS knowledge scale as opposed to the DAS comfort scale, but the mean scores for the scales did not differ significantly from one another and so knowledge was not more influential than comfort in influencing the between-groups difference. Apart from this between groups difference, there were no other differences of significance between groups. Overall across groups, individuals reported generally high rates of acceptance and comfort around dementia (DAS). Individuals reported generally low levels of stigma on the PRISM-PC Dementia Subscale. Individuals reported moderate-to-low rates of depression, anxiety and stress, with no significant between-groups differences on the DASS. Therefore the groups did not differ significantly from one another on any of the explicit measures.

Correlation analysis of questionnaires between IRAP trial-types and questionnaire data found no overall significant correlations. This may suggest that the IRAP responses did not significantly relate to any questionnaire data. One may suggest this is consistent with existing research that suggests that typically within socially sensitive domains, there is a lack of correlation between IRAP scores and explicit measures (Barnes-Holmes et al., 2010). In relation to the REC model outlined in the introduction, the differences in effects indicate that automatic evaluative responses (or BIRRs) on the IRAP did not cohere with more elaborate and extended relational responding on the self-report measures. Therefore one may suggest overall that IRAP effects did not significantly relate to the findings of the explicit measures. Implications of this are discussed in greater detail further in this discussion. In future, IRAP researchers should give more consideration to the specific purposes of conducting detailed correlational analysis between implicit and explicit measures.

There were no significant correlations between DASS scores and responses to the MBI or SEWRD-Q, as was hypothesised. This may be due to care-workers reporting low levels of burnout (MBI) or industry-related stress (SEWRD-Q), or by moderate-to-low reported experiences of depression, anxiety or stress. The lack of strong responses to these scales may indicate that care-worker samples did not experience notably high or low levels of depression, anxiety, stress or burnout. There was a positive correlation between the DAS and the SEWRD-Q indicating that more positive attitudes towards people with dementia was associated with higher levels of staff satisfaction. Combined with the finding reported above that lower levels of burnout were related to less dementia stigma; this further supports the suggestion that job satisfaction influences dementia stigma, as was found by Moyle et al. (2010). Therefore one may suggest that overall, the questionnaire scores did not correlate with one another significantly, as was hypothesised.

When conducting analyses with a large number of variables in a correlation matrix, there may be a higher risk of type II error rates when applying corrections for multiple comparisons (Perneger, 1998). In order to reduce this type II error risk, an uncorrected .05 alpha level was included in analysis. Results at this uncorrected alpha level found significant positive correlations between PRISM-independence scale with the *dementia-negative* trial type. Analysis indicated that higher score on the PRISM-independence scale correlated with a higher score on the *dementia-negative* trial-type. They correlated significantly which suggests that participants who showed implicit negative bias towards people with dementia tended to show explicit beliefs that if they had dementia they would lack independence. This finding can be supported by existing literature, which suggests individuals typically view those with dementia as lacking independence (Werner and Davidson, 2004; Clare, 2003). There was a significant negative correlation between the *dementia-positive* trial-type and the MBI depersonalisation scale. As the significance for the MBI correlation was low relative to the type-1 error risk (.043), it may be spurious to infer a meaningful relationship. As negative D-IRAP for the *dementia-positive* trial-type responses indicated stronger dementia-positive biases, results indicated that as dementia-positive D-IRAP responses increased, so too did depersonalisation scales. There was a significance noted between the SEWRD-Q others' expectations scale and the '*healthy-positive*' trial. There was a significant positive correlation identified between the PRISM acceptance scale and the *healthy-positive* trial type. These effects should be examined with more scrutiny in further research, however it should be noted that significances can often tend to be spurious when performing large correlational analyses on small sample sizes. At an uncorrected alpha level of .05, there was a higher risk of Type I error, therefore indicating it may be necessary to consider the more conservative alpha level of .000625 as being more representative of true effects.

Conceptual issues related to the power of the study

A primary element of the results that must be discussed is the low statistical power of this study and the inferences that can be made relative to this low power. The study suffers from a low sample size, of only 23 non-careworkers and 17 careworkers. Lower sample sizes in statistical analysis can lead to observed effects where true effects do not exist. For this reason, statistical power was assessed for these tests. Unreported analyses of the power of findings was applied within the study indicating relatively low powers for all analyses except in relation to between-groups analysis of the *'dementia-positive'* trial type, which yielded strong statistical power, relative to Cohen's (1988) recommended standard minimum power of .8. Crucially it must be noted that one of the primary analyses of focus in this study, the between groups IRAP analyses, may have possessed a low statistical power for both main effects and interaction effects between IRAP scores and group. A low powered analysis, such as that performed in the between-groups assessment, would run the risk of identifying a statistically significant difference when true effects do not exist. In the current case therefore, one must note that significant effects identified within the analysis may be spurious. There may not have been a significant difference in *D-IRAP* scores between the careworkers and non-careworkers, due to the low power of this analysis.

However one must note a significant finding between groups that was identified as being highly powered, and remained significant under adjusted alpha levels; the *dementia-positive* trial type. As this trial type was identified as being significant under adjusted alpha levels and highly powered, one may suggest findings may represent a true effect where one was identified. The fact that this trial type yielded significant between groups difference may have had a substantial influence on overall between-group findings, which may account for the fact that at an uncorrected alpha level of .05, overall between groups effects would have been considered significant. Furthermore, as the *'dementia – positive'* trial type was

significantly different between groups under corrected alphas, this may have acted as an indication as to why significance may have been observed at this uncorrected level (.05). As such, one may suggest conducting Bonferroni comparisons lead to a reduction in the risk of Type 1 error within the current experiment, suggesting that as Bonferroni corrected alpha levels were applied throughout this analysis, the findings were less likely to produce significant effects where true effects did not exist.

Consideration of the power also should be made in relation to the questionnaire measures. While the REC model may provide a conceptual explanation for variances in responding across implicit and explicit measures, it may be necessary to apply a level of scrutiny in relation to how much can be inferred from the current findings. In analysing the questionnaire data, unreported post-hoc power analyses yielded that the largest achieved power in the correlation matrix was low relative to the minimum standard of .8, outlined by Cohen (1988). For this aforementioned most powerful finding, a sample size of 50 would have been required to meet this minimum power level. The lower sample size would lead to a risk of type II error rate, whereby a statistically significant effect is not observed, where a true effect exists. One may suggest that with a sample of 40 participants, the study was underpowered. As such, it may be suggested that running a larger number of participants in future research may allow for less risk of type II error rate, and potentially stronger statistical power in findings. IRAP research may be suggested to lack consistency in relation to reporting whether studies possessed strong power or not. As such, future IRAP studies should strive to address and discuss the statistical power of findings (see Vahey et al., 2013 for a more detailed discussion of statistical power in IRAP research).

Conceptual considerations related to results

Literature on the IRAP and other implicit measures such as the IAT typically propose that the rationale for applying implicit analysis is that implicit tools may be able to measure responses, such as relational responses corresponding to one's verbal history, which may not be measured by explicit tools, such as questionnaires; particularly in cases whereby the domain being analysed is socially sensitive (Barnes-Holmes et al., 2010). This further falls into the REC model, as is previously described, and accounts for how variance can occur in relation to results from explicit and implicit tests, whereby brief or immediate responses (BIRRs) which occur at shorter latencies following presentation of the trial stimuli are suggested to correspond more readily with an individual's relational learning history (Barnes-Holmes et al., 2010). Therefore within the RFT interpretation of results, if an analysis is conducted which detects effects on an implicit test which are simultaneously not identified by the corresponding explicit measures, the rationale proposed by literature on implicit testing would argue that this may be a result of the superiority of the implicit test, as opposed to the explicit test, in measuring the rate of bias; however one may also argue that this may merely be a reflection of a lack of statistical power to detect this correlation (as may be the case in the current study). Therefore in the current analysis, researchers who support this rationale for inferring effects may suggest that the IRAP was effective in analysing forms of responding in relation to dementia, that were not as effectively measured in the explicit questionnaire tests, even though this may be the mere consequence of low statistical power.

However it may be suggested that this is a confirmatory approach to identifying the bias. The low power of this current study would mean a higher risk of Type II error rate. As such, a significant correlation was less likely to be identified between IRAP trial types and questionnaire scales. Within the rationale described above, this low power would therefore serve to substantiate the results of the IRAP in more effectively assessing biases than

questionnaires. It must be noted however that this may be suggested be confirmatory in identifying effects. Effectively the low power of the current study as a result of a low N made it difficult to make large inferences in relation to whether a dementia stigma was identified. While literature may support the argument that implicit tests are more effective in assessing stigmas than explicit measures, the lack of correlation within the current study, coupled with the low power, indicate that it may be necessary to be conservative in inferring the veracity of results.

It should be noted that the explicit measures were introduced as previously validated measures within literature, so as to conduct comparisons between the IRAP and existing validated measures. As no correlations were identified at the adjusted alpha level, this may indicate that it is necessary to be cautious when making inferences regarding the specific findings of the IRAP used in this study. This is a conceptual issue across implicit testing literature, which should lead one to be conservative in the length to which results of implicit tests can be suggested to be valid, when not significantly correlated with explicit measures.

Further considerations related to the study

The data presented from the test phase relate specifically to the latency measured within the IRAP. This is due to the methodology of the IRAP and IAT which traditionally do not measure accuracy in test phases. Accuracy in responses is trained within the training blocks so that responding occurs at an average accuracy of 80%. Firstly, in relation to the IRAP, traditionally latency is the metric with which specific focus is applied, which is transformed into a D-IRAP score (Barnes-Holmes et al., 2010). *D-IRAP* scores function as a result of the algorithm outlined within Barnes-Holmes et al (2010), which is why typically within IRAP papers, the latency measure is discussed with more focus than the accuracy

measure. This is also typical of other implicit measures such as the IAT and Go-No Go tasks, which assess latency as their primary metric (O'Shea et al., 2016).

A conceptual motivation for analysing latency as a metric within the IRAP corresponds to the REC model as previously mentioned (Barnes-Holmes et al., 2010). The REC model of BIRRs and EERRs focuses on the speed of a response, not the accuracy of a response (Barnes-Holmes et al., 2010), which may contribute to IRAP research analysing latency as the primary datum, over accuracy. Furthermore, the IRAP and IAT train people to reach a criteria of accuracy, so the differences emerge in terms of time. Due to the inclusion criteria being set at 80% following trials, the variances in accuracy across participants would be low relative to the varying latency for participants across rules.

However it must be noted that this may be a procedural limitation of implicit tests such as the IRAP or IAT. Accuracy may be suggested to be a more traditionally behavioural measure. The relevance of accuracy scores can be observed independent of the conceptual parameters of D-IRAP scores, i.e., the latency measures within the IRAP may be suggested to be primarily relevant when analysed conceptually relative to the REC model and BIRRs. As such, presenting accuracy scores within future IRAP papers is a consideration necessary to make.

One consideration to be made is that applying a socially sensitive topic to populations, particularly those who work in the area of dementia, may produce responses that are considered to be more socially acceptable, and often less representative of an individual's actual biases towards that topic. This may be true across both explicit and implicit research. Much research on questionnaire responses has suggested that when analysing socially sensitive topics, questionnaires tend to produce misrepresentative results, as individuals tend to provide socially appropriate answers (Crosby, Bromley, & Saxe, 1980) Research has

further suggested implicit measures also suffer from difficulty in assessing socially sensitive topics (Greenwald, Poehlman, Uhlmann, & Banaji, 2009). It is suggested however within literature that dissociation between explicit and implicit measures may be seen, whereby often implicit measures can produce more accurate results than explicit measures, in relation to socially sensitive domains (Dovidio, 1992; Dovidio, Kawakami, Johnson, Johnson, & Howard, 1997).

A further consideration which may be made is studies on the IRAP which have demonstrated methodological flaws within the IRAP. One such limitation suggested within research is a positive framing bias, whereby it has been suggested that IRAP scores could be influenced by the manner in which the task was framed, indicating a positive framing bias (O'Shea et al., 2016). Further criticisms of the IRAP within literature have suggested that the IRAP may be fakeable (Drake, Seymour & Habib, 2016). A study conducted to test this instructed certain groups of participants to fake scores, and not others, with both producing scores predicted by whether or not this instruction was provided (Drake et al., 2016). As such one may suggest that it may be necessary to be conservative when inferring effects as measured by the IRAP. Research has demonstrated the IRAP may be highly prone to biases which may affect responses measured within the IRAP.

A notable limitation of this study is in the age range of the two groups. The non-careworker sample was made up of adults with an age range of 18-25, whereas the careworker sample had an age range of 18-51. Non-careworkers were primarily taken from a sample of university students. While there were only four careworkers over the age of 25, it must be noted that this disproportional variance in ages across groups may have acted as confounding in responses to the measures. As research into dementia stigma has previously identified age as a variable in the rate of stigma, this must be noted as a limitation of the current study. As hypothesised, non-careworker populations also showed the strongest

negative bias towards adults with dementia. All non-careworker participants were between the ages of 18 and 25. Prior research has similarly demonstrated that younger individuals tend to possess more negative biases towards individuals suffering across a variety of psychological and behavioural difficulties, ranging from addiction to schizophrenia (Crisp, Gelder, Goddard, & Meltzer, 2005). Young adults between the ages of 16 and 19 possessed the most negative biases towards those with dementia, with negative attitudes lessening as participants got older (Crisp et al., 2005). Two possible reasons for greater stigma towards people with dementia in a younger population might be; younger adults may know very little about dementia, and have no motivation to find out more. It is known that a lack of information and knowledge perpetuates stigma (Batsch & Mittelman, 2012). The second reason may have to do with ageism as well as dementia stigma. Cullen et al. (2009) reported that university students held negative biases towards older adults; and dementia is often thought of as an older person's disease. It is possible that younger adults' negative biases towards the disease itself as well as ageing in general produced strong negative responses. This highlights the importance of educating younger adults about dementia and also healthy, positive ageing. Future research may aim to control for measuring stigma across ages.

A potential confounding variable was the use of words as the sole stimuli being used in the IRAP. It is common within IRAP designs to apply picture stimuli or simple word stimuli referring to applying only one label word. Barnes-Holmes et al (2010) have postulated that if statements are applied as label stimuli, as opposed to single word or image stimuli, the latency may need to be adjusted to 3,000ms in order to account for the extended length of time related to processing of information, inferring that the use of label stimuli using many words relies on extended latencies to respond. In this regard, the current study which applies word stimuli involving more than one word (i.e., "*healthy adults*" and "*adults with dementia*") may have involved a delayed latency due to extended length of processing. While

review of available literature has suggested the comparison of word and text stimuli within IRAP research has not been thoroughly investigated, Kelly and Barnes-Holmes (2011) suggested in comparison of word and text stimuli, IRAP effects are stronger when using images, as they produce more automatic and emotive responses, and have more ecological validity. When designing the current study, based on the findings of Cullen et al (2009), it was deemed necessary to use word stimuli so as to avoid ageist attitudes as a confound. Future IRAP research analysing stigma towards dementia may benefit from the use of more direct, shorter word targets, so as to reduce the speed of processing necessary for analysis, in line with suggestions of Barnes-Holmes et al (2010), or the adaption of picture stimuli to produce more emotive responding (Kelly & Barnes-Holmes, 2011).

Conclusion

The findings of the current analysis suggest overall that there was a significant IRAP effect within participants across the four trial types, however there were not significant differences between groups. Therefore whether or not an individual had professional experience with those with dementia did not impact their biases towards dementia, as there were no significant differences overall between groups. Furthermore proving the reliability of the significant effects that were found, in relation to the *dementia - positive* trial type, requires further examination in future research. Results demonstrated that there was not a significant relationship between the IRAP and explicit measures. One may suggest that a primary limitation of this study may have been the low power, indicating a risk of type II error rates, as well as a low sample size of forty. Future research into dementia stigma applying the IRAP, or indeed other forms of implicit testing, may be needed in order to determine the validity of the current findings, and should also consider acquiring larger sample sizes. Overall one may suggest that while some level of implicit bias towards those with dementia may exist, it may not be mediated by experience with individuals with

DEMENTIA & STIGMA IRAP

dementia. Further considerations related to selection of stimuli and explicit measures may be made in order to advance our understanding of explicit and implicit stigma towards dementia.

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APPENDICES

Appendix 1: Information sheet



INFORMATION SHEET PLEASE KEEP THIS PAGE FOR YOUR INFORMATION **Research Topic: Analysis of stigma toward dementia**

Information sheet for participants:

Thank you for agreeing to participate in this study which is being conducted as part of my Masters of Science in Psychology degree. I am a currently registered student in the Department of Psychology, in Maynooth University. My name is Alan Kane, I have a BA (Hons.) Psychology degree, and I am the primary researcher involved in this study. I am working under the supervision of Dr Carol Murphy and Dr Michelle Kelly of the Department of Psychology, Maynooth University (see contact details at the end of this sheet).

Why is this research being carried out?

This research aims to assess whether stigma or negative attitudes toward dementia are shown for different participant groups (i.e., young and older participants who are not careworkers; a sample of careworkers working with adults with dementia). Also, organisations supporting people with dementia (e.g., Alzheimer Society, Ireland) provide educational information in video form to reduce stigma among staff and for the general public. This study will assess whether stigma exists against adults with dementia; whether age is a variable in this, and whether the video provided is effective in reducing stigma.

Who can participate?

Community dwelling adults, aged 18-30 and aged 50-65, who are not working with people with dementia.

Individuals who are currently working with adults with dementia are invited to participate in this study.

Who should not participate, and is there any risk?

You are advised not to participate if you have a visual impairment that is not corrected with lenses, or if you have a history of seizures or photosensitive epilepsy (because the research involves viewing a computer-screen).

If you are between 30 and 50 years you should not participate as you fall between young versus older age-groups.

What does participation involve?

You will be asked to complete a computer-based task with onscreen presentation of positive or negative words in relation to dementia. Sometimes you will be asked to respond with "True" and sometimes with "False", and you should respond quickly whether you agree or not. The researcher will help you with practice trials at first.

You will also be asked to complete a number of questionnaires. Some of these relate to your current mood or anxiety level, however, you should not consider this an intervention of any kind. The researcher is not qualified in clinical assessment, and the (anonymised) data will be used only for research purposes. Other questionnaires will assess attitudes towards dementia.

Length of study

Participation may involve 1 or 2 sessions lasting roughly 1½ to 2 hours. The second session will involve viewing a brief (15 mins.) educational video about dementia and then repeating the original assessments. To avoid inconvenience or boredom for participants, the second session may be conducted on a separate occasion. Only the group showing the stronger negative bias toward dementia in the initial assessments will be asked to complete the second session.

Confidentiality

You and your agency will not be identified in any presentation or published research article. All assessment data are recorded using a code, and not your name, and all data analysis is conducted at group level, not at an individual level.

With permission of the participant, contact information and the group you were assigned to (e.g., young noncareworker; older noncareworker; careworker) may be taken. This information will be kept in an encrypted file on a password-protected PC until your participation is complete. This is because you may be asked to complete a second session. This file will be permanently destroyed by the researcher at the point of data analysis.

Voluntary

Your participation is entirely voluntary; you are not obliged to take part and can withdraw participation at any stage without penalty of any description. You might not be able to withdraw your data, however, because it may be unidentifiable.

What will happen to the data?

The anonymised data will be used as part of a Masters Degree thesis and may be published in an academic journal.

Contact details

Researcher:

Alan Kane
alan.kane.2013@mumail.ie
0868880690

Supervisors

Dr. Carol Murphy, BCBA-D.
carol.a.murphy@nuim.ie
01-7086723

Dr. Michelle Kelly, BCBA-D.
Michelle.E.Kelly@nuim.ie
01-4747470

Ethics and research

When conducting the research, the researcher will adhere to current ethical standards dictated by the Psychological Society of Ireland and the British Psychological Society.

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Appendix 2: consent form



CONSENT FORM

Research Title: Analysis of attitudes toward dementia

Researcher: Alan Kane, BA (Hons.) Psych., is a currently registered student at the Department of Psychology, Maynooth University, and will conduct the research as part of a Master’s Degree thesis.
Email: Alan.Kane@nuim.ie

Supervisor(/s): Dr. Carol Murphy, Dr. Michelle Kelly, Department of Psychology, MU
Email: Carol.A.Murphy@nuim.ie Tel: 01 708 6723 Michelle.E.Kelly@nuim.ie

For Participant:

I(please print name) understand the following:

My participation is completely voluntary and I can withdraw at any time; but I may not be able to withdraw my data because it may not be identifiable.

Confidentiality is assured and neither my name nor the name of my place of work will appear on any resultant publication.

I may be asked to complete 1 or 2 research sessions and the researcher will retain my contact information until the point of data analysis, then this information will be destroyed.

I have been advised not to take part in this study if I have a history of photo-sensitive epilepsy, as this research involves viewing a computer screen which may pose a negligible risk.

I have also read and understand the Information Sheet provided with this consent form, and I agree to participate in the research.

Signature:

Date: _____

NB: If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

Appendix 3: DAS

Dementia Attitudes Scale

Is it rewarding to work with people who have Alzheimer's disease and related dementias (ADRD).

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I am afraid of people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

People with ADRD can be creative.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I feel confident around people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I am comfortable touching people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I feel uncomfortable being around people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

Every person with ADRD has different needs.

DEMENTIA & STIGMA IRAP

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I am not very familiar with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I would avoid an agitated person with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

People with ADRD like having familiar things nearby.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

It is important to know the past history of people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

It is possible to enjoy interacting with people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I feel relaxed around people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

People with ADRD can enjoy life.

1 2 3 4 5 6 7

DEMENTIA & STIGMA IRAP

Strongly Disagree Strongly Agree

People with ADRD can feel when others are kind to them.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I feel frustrated because I do not know how to help people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I cannot imagine caring for someone with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

I admire the coping skills of people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

We can do a lot now to improve the lives of people with ADRD.

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

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

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

Appendix 4

Fraboni Scale of Ageism

Complex and interesting conversation cannot be expected from most people with dementia

Strongly Disagree 1 2 3 4 5 Strongly Agree

People with dementia are respected for their wisdom

Strongly Disagree 1 2 3 4 5 Strongly Agree

Most people with dementia would be considered to have poor personal hygiene

Strongly Disagree 1 2 3 4 5 Strongly Agree

Most people with dementia can be irritating because they tell the same stories over and over again

Strongly Disagree 1 2 3 4 5 Strongly Agree

People with dementia live mostly independently

Strongly Disagree 1 2 3 4 5 Strongly Agree

People with dementia don't really need to use our community facilities

Strongly Disagree 1 2 3 4 5 Strongly Agree

It is best that people with dementia live where they won't bother anyone

Strongly Disagree 1 2 3 4 5 Strongly Agree

The company of most people with dementia is quite enjoyable

Strongly Disagree 1 2 3 4 5 Strongly Agree

I would try and avoid eye contact with someone if I thought they had dementia

Strongly Disagree 1 2 3 4 5 Strongly Agree

People with dementia pass on valued traditions

DEMENTIA & STIGMA IRAP

Strongly Disagree 1 2 3 4 5 Strongly Agree

I don't like when people with dementia try to make conversation with me

Strongly Disagree 1 2 3 4 5 Strongly Agree

I personally would not like to spend much time with a person with dementia

Strongly Disagree 1 2 3 4 5 Strongly Agree

People with dementia participate in a wide variety of activities and interests

Strongly Disagree 1 2 3 4 5 Strongly Agree

People with dementia are a good source of knowledge

Strongly Disagree 1 2 3 4 5 Strongly Agree

I would prefer not to go to a social group if people with dementia were also invited

Strongly Disagree 1 2 3 4 5 Strongly Agree

People with dementia receive priority in care

Strongly Disagree 1 2 3 4 5 Strongly Agree

I wouldn't bother visiting a person with dementia because they wouldn't remember that I came

Strongly Disagree 1 2 3 4 5 Strongly Disagree

People with dementia have care and concern for other people

Strongly Disagree 1 2 3 4 5 Strongly Agree

There is no point in talking to someone with dementia because they can't take in what I say

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would not want my family to know

DEMENTIA & STIGMA IRAP

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would feel humiliated

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would no longer be taken seriously

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would be considered stupid and unable to do things

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would be ashamed or embarrassed

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would be depressed

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would be anxious

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would give up on life

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia my doctor would not provide the best care for my other medical problems

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia my doctor and other health professionals would not listen to me

Strongly Agree 1 2 3 4 5 Strongly Agree

If I had dementia I would not want my health insurance company to find out

DEMENTIA & STIGMA IRAP

Strongly Disagree 1 2 3 4 5 Strongly Agree

If I had dementia I would not want my employer to find out

StronglyDisagree 1 2 3 4 5 Strongly Agree

Appendix 5

Perceptions Regarding Investigational Screening in Primary Care (PRISM-PC).

I would like to know if I am at higher risk than others of developing Alzheimer's disease.

Strongly disagree 1 2 3 4 5 Strongly agree

I would like to know if I have Alzheimer's disease

Strongly disagree 1 2 3 4 5 Strongly agree

I would like to know if I have a problem with memory

Strongly disagree 1 2 3 4 5 Strongly agree

I would like to be tested for the presence of Alzheimer's disease on a regular basis with a short questionnaire.

Strongly disagree 1 2 3 4 5 Strongly agree

I would like to be tested for the presence of Alzheimer's disease on a regular basis with a blood sample.

Strongly disagree 1 2 3 4 5 Strongly agree

I would like to be tested for the presence of Alzheimer's disease on a regular basis with pictures of my head or brain (CT-scan or MRI).

Strongly disagree 1 2 3 4 5 Strongly agree

I would like a doctor to examine me every year to know if I have developed memory problems.

Strongly disagree 1 2 3 4 5 Strongly agree

I would like a doctor to examine me every year to know if I have developed Alzheimer's disease.

DEMENTIA & STIGMA IRAP

Strongly disagree 1 2 3 4 5 Strongly agree

I would like a doctor to examine me every year to know if I have developed colon cancer.

Strongly disagree 1 2 3 4 5 Strongly agree

I would like a doctor to examine me every year to know if I have developed depression.

Strongly disagree 1 2 3 4 5 Strongly agree

I do not believe that treatment for Alzheimer's disease is currently available.

Strongly disagree 1 2 3 4 5 Strongly agree

I believe that early detection of Alzheimer's disease increases the chance to treat the disease better.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, my family would suffer financially.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, my family would suffer emotionally.

Strongly disagree 1 2 3 4 5 Strongly agree

If I knew that I had Alzheimer's disease earlier, my family would have a better chance to take care of me.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would not want my family to know

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would feel humiliated by my family members and/or others who would treat me poorly or laugh at me.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would no longer be taken seriously.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would be considered stupid and unable to do things.

Strongly disagree 1 2 3 4 5 Strongly agree

If I knew that I had Alzheimer's disease, I would be ashamed or embarrassed.

Strongly disagree 1 2 3 4 5 Strongly agree

If I knew that I had Alzheimer's disease, I would be depressed.

Strongly disagree 1 2 3 4 5 Strongly agree

If I knew that I had Alzheimer's disease, I would be anxious.

Strongly disagree 1 2 3 4 5 Strongly agree

If I knew that I had Alzheimer's disease, I would give up on life.

Strongly disagree 1 2 3 4 5 Strongly agree

If I found out early that I had Alzheimer's disease, I would have more time to plan my future.

Strongly disagree 1 2 3 4 5 Strongly agree

If I found out early that I had Alzheimer's disease, I would have more time to talk with my family about my health care.

Strongly disagree 1 2 3 4 5 Strongly agree

If I found out early that I had Alzheimer's disease, I would have more time to talk with my family about my finances.

Strongly disagree 1 2 3 4 5 Strongly agree

If I found out early that I had Alzheimer's disease, I would sign my advance directive or my living-will.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, my doctor would not provide the best care for my other medical problems.

Strongly disagree 1 2 3 4 5 Strongly agree

If I knew that I had Alzheimer's disease earlier, I would be motivated to have a healthier lifestyle.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, my doctor and other health professionals would not listen to me.

Strongly disagree 1 2 3 4 5 Strongly agree

If I knew that I had Alzheimer's disease earlier, I would be more willing to participate in research about this disease.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would not be able to get health insurance.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would be concerned that my health insurance company would find out.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would be concerned that my employer would find out.

Strongly disagree 1 2 3 4 5

If I had Alzheimer's disease, I would not be able to get life insurance.

Strongly disagree 1 2 3 4 5

If I had Alzheimer's disease, I would not be able to get long-term care insurance.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would lose my home.

DEMENTIA & STIGMA IRAP

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would be living in a nursing home.

Strongly disagree 1 2 3 4 5 Strongly agree

If I had Alzheimer's disease, I would lose my driver's license and other privileges.

Strongly disagree 1 2 3 4 5 Strongly agree

Appendix 6

Depression Anxiety Stress Scale (DASS)

Report your experiences within the last week.

I felt downhearted and blue

Over the last week...

Most of the time 1 2 3 4 Never

I felt sad and depressed

Over the last week...

Most of the time 1 2 3 4 Never

I could see nothing in the future to be hopeful about

Over the last week...

Most of the time 1 2 3 4 Never

I felt I had nothing to look forward to

Over the last week...

Most of the time 1 2 3 4 Never

I felt that life was meaningless

Over the last week...

Most of the time 1 2 3 4 Never

I felt that life wasn't worthwhile

Over the last week...

Most of the time 1 2 3 4 Never

I felt I was pretty worthless

Over the last week...

Most of the time 1 2 3 4 Never

I felt I wasn't worth much as a person

Over the last week...

Most of the time 1 2 3 4 Never

I felt that I had lost interest in just about everything

Over the last week...

Most of the time 1 2 3 4 Never

I was unable to become enthusiastic about anything

Over the last week...

Most of the time 1 2 3 4 Never

It seemed I couldn't experience any positive feeling at all

Over the last week...

Most of the time 1 2 3 4 Never

I couldn't seem to get any enjoyment out of the things I did

Over the last week...

Most of the time 1 2 3 4 Never

I just couldn't get going

Over the last week...

Most of the time 1 2 3 4 Never

I found it difficult to work up the initiative to do things

Over the last week...

Most of the time 1 2 3 4 Never

I was aware of the action of my heart in the absence of physical exertion (e.g, sense of heart rate increase, heart missing a beat)

Over the last week...

Most of the time 1 2 3 4 Never

I perspired noticeably (e.g. hands sweaty) in the absence of high temperatures or physical exertion

Over the last week...

Most of the time 1 2 3 4 Never

I was aware of dryness in my mouth

Over the last week...

Most of the time 1 2 3 4 Never

I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)

Over the last week...

DEMENTIA & STIGMA IRAP

Most of the time 1 2 3 4 Never

I had difficulty in swallowing

Over the last week...

Most of the time 1 2 3 4 Never

I had a feeling of shakiness (e.g. legs going to give way)

Over the last week...

Most of the time 1 2 3 4 Never

I experienced trembling (e.g. in the hands)

Over the last week...

Most of the time 1 2 3 4 Never

I was worried about situations in which I might panic and make a fool of myself

Over the last week...

Most of the time 1 2 3 4 Never

I found myself in situations which made me so anxious I was most relieved when they ended

Over the last week...

Most of the time 1 2 3 4 Never

I feared that I would be "thrown" by some trivial but unfamiliar task

Over the last week...

Most of the time 1 2 3 4 Never

I felt I was close to panic

Over the last week...

Most of the time 1 2 3 4 Never

I felt terrified

Over the last week...

Most of the time 1 2 3 4 Never

I felt scared without any good reason

Over the last week...

Most of the time 1 2 3 4 Never

I had a feeling of faintness

Over the last week...

Most of the time 1 2 3 4 Never

I found it hard to wind down

Over the last week...

Most of the time 1 2 3 4 Never

I found it hard to calm down after something upset me

Over the last week...

Most of the time 1 2 3 4 Never

I found it difficult to relax

Over the last week...

Most of the time 1 2 3 4 Never

I felt that I was using a lot of nervous energy

Over the last week...

Most of the time 1 2 3 4 Never

I was in a state of nervous tension

Over the last week...

Most of the time 1 2 3 4 Never

I found myself getting upset rather easily

Over the last week...

Most of the time 1 2 3 4 Never

I found myself getting upset by quite trivial things

Over the last week...

Most of the time 1 2 3 4 Never

I found myself getting agitated

Over the last week...

Most of the time 1 2 3 4 Never

I tended to over-react to situations

Over the last week...

DEMENTIA & STIGMA IRAP

Most of the time 1 2 3 4 Never

I found that I was very irritable

Over the last week...

Most of the time 1 2 3 4 Never

I felt that I was rather touchy

Over the last week...

Most of the time 1 2 3 4 Never

I was intolerant of anything that kept me from getting on with what I was doing

Over the last week...

Most of the time 1 2 3 4 Never

I found myself getting impatient when I was delayed in any way (e.g. lifts, traffic lights, being kept waiting)

Over the last week...

Most of the time 1 2 3 4 Never

I found it difficult to tolerate interruptions to what I was doing

Over the last week...

Most of the time 1 2 3 4 Never

Appendix 7

Maslach Burnout Inventory

I feel emotionally drained from my work

Never 1 2 3 4 5 6 7 Always

I feel used up at the end of the workday

Never 1 2 3 4 5 6 7 Always

I feel fatigued when I get up in the morning and have to face another day on the job

Never 1 2 3 4 5 6 7 Always

Working with people all day is really a strain for me

Never 1 2 3 4 5 6 7 Always

I feel burned out from my work

Never 1 2 3 4 5 6 7 Always

I feel frustrated by my job

Never 1 2 3 4 5 6 7 Always

I feel I'm working too hard on my job

Never 1 2 3 4 5 6 7 Always

Working with people directly puts too much stress on me

Never 1 2 3 4 5 6 7 Always

I feel like I'm at the end of my rope

Never 1 2 3 4 5 6 7 Always

I can easily understand how my recipients feel about things

DEMENTIA & STIGMA IRAP

Never 1 2 3 4 5 6 7 Always

I deal very effectively with the problems of my recipients

Never 1 2 3 4 5 6 7 Always

I feel I'm positively influencing other people's lives through my work

Never 1 2 3 4 5 6 7 Always

I feel very energetic

Never 1 2 3 4 5 6 7 Always

I can easily create a relaxed atmosphere with my recipients

Never 1 2 3 4 5 6 7 Always

I feel exhilarated after working closely with my recipients

Never 1 2 3 4 5 6 7 Always

I have accomplished many worthwhile things in this job

Never 1 2 3 4 5 6 7 Always

In my work, I deal with emotional problems very calmly

Never 1 2 3 4 5 6 7 Always

I feel I treat some recipients as if they were impersonal "objects"

Never 1 2 3 4 5 6 7 Always

I've become more callous toward people since I took this job

Never 1 2 3 4 5 6 7 Always

I worry that this job is hardening me emotionally

Never 1 2 3 4 5 6 7 Always

I don't really care what happens to some recipients

Never 1 2 3 4 5 6 7 Always

I feel recipients blame me for some of their problems

Never 1 2 3 4 5 6 7 Always

I feel similar to my recipients in many ways

Never 1 2 3 4 5 6 7 Always

I feel personally involved with my recipients' problems

Never 1 2 3 4 5 6 7 Always

I feel uncomfortable about the way I have treated some recipients

Never 1 2 3 4 5 6 7 Always

Appendix 8

Staff Experience of Working with Residents with Dementia

To what extent do you experience satisfaction in your work?

Never 1 2 3 4 5 6 7 Always

To what extent can you respond to expectations from patient's relatives?

Never 1 2 3 4 5 6 7 Always

To what extent do you feel satisfaction in contact with dementia patients?

Never 1 2 3 4 5 6 7 Always

To what extent do you experience the contact with a confused patient as stimulating?

Never 1 2 3 4 5 6 7 Always

To what extent do you find the contact with a patient in his terminal state as stimulating?

Never 1 2 3 4 5 6 7 Always

To what extent does the work function well between day-staff and night-staff?

Never 1 2 3 4 5 6 7 Always

To what extent is your ward sister a good one?

Never 1 2 3 4 5 6 7 Always

To what extent are your expectations from work satisfied?

Never 1 2 3 4 5 6 7 Very satisfied

To what extent are the supervisory staff good as work-organisers?

Never 1 2 3 4 5 6 7 Excellent

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To what extent do you experience satisfaction in your social life?

Never 1 2 3 4 5 6 7 Always

To what extent do relatives of dementia patients respond well to your treatment of them?

Never 1 2 3 4 5 6 7 Always

To what extent can you be helpful and see the needs of a patient with dementia?

Never 1 2 3 4 5 6 7 Always

To what extent do you find your work rewarding?

Never 1 2 3 4 5 6 7 Always

When you feel satisfied with your work, to what extent is this feeling experienced?

Never 1 2 3 4 5 6 7 Always

To what extent do you respond to the expectations of your colleagues?

Never 1 2 3 4 5 6 7 Always

To what extent do you respond to the expectations of your supervisory staff?

Never 1 2 3 4 5 6 7 Always

How often do you feel strain in the contact with dementia patients?

Never 1 2 3 4 5 6 7 Always

Are you satisfied with your work goals?

Never 1 2 3 4 5 6 7 Very satisfied

To what extent do your colleagues respond to your expectations?

Never 1 2 3 4 5 6 7 Always

To what extent is your workplace ideal for the care of dementia patients?

Never 1 2 3 4 5 6 7 Excellent

