The Extent by which Self-Identity Dimensions can be Ascertained in People Living with Dementia admitted to an Acute Psychiatric Hospital using a Culturally Adapted Self-Identity in Dementia Questionnaire:
A Feasibility Study.

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Abstract

There are approximately 850,000 people in the United Kingdom (UK) with dementia (Alzheimer's Society, 2013). Dementia is a progressive disorder caused by brain disease or injury, marked by cognitive, behavioural and personality changes. Support should be sensitive to the person as an individual, including their life history, personality, likes and dislikes, and focus on promoting their well-being. How to identify what is important to the person living with dementia can be challenging, particularly at an acute stage of the disease when behavioural or psychological symptoms emerge and self-identity is at risk as the disease progresses.

Self-Identity in Dementia:

A literature review on measurement of self-identity in dementia demonstrated the current evidence base is predominantly from the United States, originates from nursing or residential settings, and is not validated within a UK, NHS secondary care setting. One tool which might be useful to adapt for use within the UK is the Self-Identity in Dementia Questionnaire (SIDQ) developed in Israel by Cohen-Mansfield, Golander and Arnheim (2000). The SIDQ is a multi-informant self-completion questionnaire comprising four self-identity dimensions; occupation, family, hobbies and activities, and personal attributes.

Aims and Objectives:

Implement a culturally-adapted version of the Self-Identity in Dementia Questionnaire to multiple informers (individuals living with dementia, informal carers and formal carers) admitted to an acute NHS psychiatric admissions ward,

to determine acceptability and practicality as well as usefulness in identifying self-identity, and the strength and levels of agreement between the individual, informal carer and formal carer.

Methods:

Co-design through patient and public involvement resulted in the development of an adapted version of the SIDQ questionnaire. Multi-informant recruitment and consent from the three participant groups was obtained, adhering to the ethical guidance from the Mental Capacity Act (Department of Health, 2005).

Results:

Thirty-six participants, (15 individuals living with dementia, 15 informal carers and 6 formal carers) provided 15 complete data sets of the Adapted Self-Identity in Dementia Questionnaire (Adapted-SIDQ). The Adapted-SIDQ was able to educe self-identity data from all participants, including those with moderate to advanced dementia. Key findings related to family role, gender-specific roles, hobbies and activities, use of an individual's name, low levels of agreement between informants, and the impact of different time frames on importance levels to inform therapeutic intervention.

Conclusion:

It was feasible to use the Adapted-SIDQ as a research tool, effectively ascertaining an individual's self-identity in those people living with dementia ranging from mild to severe stages. A critical evaluation of its implementation determined challenges with recruitment of informal carers and its acceptability and practicalities as a clinical tool. Methods of research engagement to improve

recruitment in future were identified, including earlier involvement in study design with facilitation and further support throughout the study.

Investigating self-identity in dementia with the Adapted-SIDQ concluded it is identifiable and measurable, and acceptable, yet further research is required to determine demand for in, and its integration into, clinical practice.

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Declaration

'*Whilst registered as a candidate for the above degree, I have not been registered for any other research award. The results and conclusions embodied in this thesis are the work of the named candidate and have not been submitted for any other academic award.*'

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Acknowledgements and Dedication

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Dissemination

Murray, A. (2013). The mental capacity act and dementia research. *Nursing Older People*, 25 (3), 14-20.

Murray, A. (2014). The effect of dementia on patients, informal carers and nurses. *Nursing Older People*, 26 (5), 27-31.

Research Seminar Series, July 2015. Presentations on Dementia by Postgraduate Researchers at the School of Health Sciences and Social Work, University of Portsmouth: '*The preservation of self-identity by people with dementia*'.

Poster presentation: '*The preservation of self-identity in people with dementia in acute psychiatric assessment care*' at Dementia Congress, 3-5th November 2015, Telford.

Wessex Regional Frailty Conference, '*Preserving Self-Identity in the Older Adult'*, 3rd March 2016.

University of Portsmouth Aging Network Inaugural Conference. Panel Discussion. '*How to do dementia research*', 28th June 2016.

Preface

Looking reflectively at my professional life, I see points of light that lent clarity to my decision to focus on dementia care, not only for my nursing career pathway, but for my doctoral thesis. One momentous experience 19 years ago, when I was a mental health student nurse, particularly stands out;

Observing a female patient standing in a corridor in an acute psychiatric assessment ward for people with dementia, I see she is talking to someone or something which cannot be seen by others. She is hunched over, concentrating, focused. She reaches out to touch something and her facial expressions change, she appears startled and then increasingly worried. She begins shouting repeatedly, verging on panic, and begins screaming loudly in a distressed manner. Other patients and relatives stop and stare, but pass her by. Her distress is escalating and she is posing a risk to herself and others. She attempts to lash out to try and stop the constant deluge of feelings and experiences that she is unable to understand and she cannot communicate her fear.

I knew this lady had severe cognitive impairment through dementia with compromised language skills, so she was unable to understand what was said to her or articulate what she was experiencing. She was unable to maintain her own safety as her ability to perceive people or objects and the spatial relationships among these was greatly impaired.

This clinical practice scenario induced a torrent of feelings in me, not only as a student nurse but also as a human being. Observing such severe distress made

me feel helpless. I was being trained to be able to support patients with severe mental health problems, but I hesitated and started questioning my ability to put into practice skills learnt. How was it best to approach her? What did I know about her and her life to try and engage her, to alleviate some of the distress she was experiencing?

I knew very little about her except the name of her husband and that they had been together since they were aged thirteen, interpreting this as she had a very strong attachment to him. Through the use of his name, simplifying my language and using soothing, calming words to enable understanding, once close enough I was able to use touch to communicate reassurance to her, so that she eventually fell against me sobbing.

Reflecting on this encounter I felt detached from my patient, questioning if I had known more about her, could I have prevented this escalating to such a distressing level? What information should I have known that could have helped earlier? I knew nothing about her personal biography, nor the emotional aspects of her illness and how it so severely affected her.

Challenging my practice induced the realisation that we can alleviate physical pain, but mental pain, despair and emotional distress through the journey of dementia is less accessible to treatment. It is connected to who we are; our personality, our character, our identity and our soul.

Dignity in care remains a central priority, reflecting my values and beliefs about best nursing practice, and I have always enjoyed a great sense of pride in the level of care I provide for my patients. I have developed an inherent, profound sense of how I would like to treat a fellow human being in a caring and compassionate

manner. I vowed to play a part for those who can truly show care and compassion in all aspects of clinical care so that no one person with dementia would experience what this courageous lady encountered on a day-by-day basis.

The core of this research study arises from these experiences: to search for greater knowledge, to continue to challenge and strive for answers, and to contribute to the improvement of nursing care and treatment for those with dementia.

"A man does not consist of memory alone. He has feeling, will, sensibilities, moral being - matters of which neuropsychology cannot speak. And it is here, beyond the realm of an impersonal psychology, that you may find ways to touch him, and change him."

A.R. Luria, from a personal letter to Oliver Sacks (1985, p.32), *The Man Who Mistook His Wife for a Hat.*

Chapter One – INTRODUCTION, CONTEXT AND RATIONALE FOR THE STUDY

Chapter One will provide an overview of the structure of the thesis, and will then discuss the context and background to dementia care including the impact of dementia on the individual, their relatives and formal carers, particularly the nursing workforce within health and social care settings. Current care and treatment approaches will be briefly described.

1.1 Structure of the thesis

Worldwide prevalence figures estimate 47.5 million people live with dementia, with this number expected to double to 75.6 million by 2030 and treble to 135.5 million by 2050 (World Health Organisation, 2016). The Alzheimer's Society (2013) estimates that there are approximately 850,000 people in the United Kingdom who are living with some form type of dementia. Living with and beyond diagnosis as dementia progresses presents a huge challenge to the individual, their relatives and friends due to increasing physical, behavioural, cognitive and personality changes, with health and social care services striving to meet complex individual needs and maintain quality of life (Royal College of Nursing, 2011).

This thesis, which forms part of the Professional Doctorate in Nursing through the University of Portsmouth, describes a feasibility study using a previously validated tool, the Self-Identity in Dementia Questionnaire (SIDQ), developed in Israel for use in nursing homes by Cohen-Mansfield, Golander and Arnheim (2000). The study explores the feasibility of culturally adapting this tool for use in a different country, with a different population and within a previously unstudied care setting –

an acute psychiatric in-patient assessment ward. This will be achieved through involving patients within a local National Health Service (NHS) acute psychiatric assessment ward, when the illness has progressed to the more advanced stages, with the possible emergence of behavioural and psychological symptoms associated with a diagnosis of dementia. Through co-design with participant representatives (individuals living with dementia, and their informal and formal carers) and a public and patient research representative group, it was envisaged that stakeholders could provide valuable insights to facilitate the development of an Adapted Self-Identity in Dementia Questionnaire (Adapted-SIDQ).This feasibility study aims to establish if the tool is acceptable and practical as a research tool, and appropriate for further testing in its adapted format as a clinical tool.

The concept of self-identity and if, or how, it can be measured and preserved is explored. The complexities of adopting one definition of self-identity are defended by Strauss (1959, p.9) who stated "*identity as a concept is fully as elusive as is everyone's sense of his own personal identity*". Applying a definition to the concept is complicated, with terms being interchangeably used for "self", such as self-awareness, self-concept, self-consciousness or selfhood (Fazio, 2008). For the purpose of this research, the description proposed by Lemme (1999) will be used in that the self is the knowledge, feelings and attitudes we have about our own being as unique, functioning individuals.

Early research into self-identity has arisen from a psychological, sociological and social constructionist perspective, with a focus on threats to self-identity in dementia, investigations of the self in care environments, and protection and preservation of self in dementia.

In 2000, Cohen-Mansfield et al. identified no previous research that specifically hypothesised the survival of self-identity in dementia, and aimed to investigate this concept with the intention of enhancing the quality of life for of people with dementia, through utilising the identified enduring sense of self. The aim was to find a means of describing self-identity and then develop a systematic method for the assessment of self-identity in dementia, resulting in a tool known as the SIDQ.

Following a quality improvement project I conducted in 2009 based on a fourteen-bedded acute psychiatric assessment in-patient ward for individuals living with dementia, the findings demonstrated that little self-identity information data was, at that time, collected to inform and influence care and treatment of those in the acute and advanced stages of the illness. There emerged an indifference regarding the value of this work and a lack of consistency in the approach by ward staff regarding the implementation of life story tools such as the "This is Me" document. This is a tool developed by the Alzheimer's Society (2015) for people going into hospital so the person living with dementia can inform the health care professionals about their needs, preferences, and likes and dislikes. The tool's purpose was to facilitate the provision of person centred care, however the use of this tool was not pursued due to the perception of staff that it was time consuming and provided only a 'snapshot' of the person. The tool did not identify information in a holistic manner, nor did it utilise all resources to complete, such as involving their carers, relatives or staff. I decided that this was an area of clinical practice that would benefit from further investigation, and the following research questions were developed.

1.2 Research questions

(i)To what extent can dimensions of self-identity in individuals with dementia be ascertained when admitted to an acute psychiatric hospital for older adults using a culturally Adapted Self-Identity in Dementia Questionnaire?

(ii) Is the culturally Adapted Self-Identity in Dementia Questionnaire an acceptable, practical and appropriate tool for use within the clinical assessment and care of individuals living with dementia?

The thesis continues with a further five chapters and a summary of each is given below:

- Chapter Two provides a critical review of the literature regarding the theoretical concepts of self-identity, and its application to dementia care to facilitate understanding of the perspectives explored later in the thesis. It outlines the methods used to conduct a review on the concept of self-identity, identity within dementia, and its subsequent measurement. It also summarises themes associated with self-identity within dementia care including threats to, and preservation of, self-identity. Lastly a discussion of self-identity, dementia and my personal philosophical stance will be outlined.

- Chapter Three outlines the methodology utilised and methods used to collect data in this two-phased feasibility research study. Phase One of the study describes the preparatory work and rationale for adaption of the SIDQ. Specific attention is drawn to the ethical considerations of applying the Mental Capacity Act (Department of Health, 2005) within this research study. Phase Two of the study describes implementation

of the Adapted Self-Identity in Dementia Questionnaire (Adapted-SIDQ), including selection of study participants and recruitment strategies employed, as well as subsequent data collection and choice of data analysis.

- Chapter Four outlines the analysis performed and presents the results from the Adapted-SIDQ, including the self-identity dimensions those living with dementia relate to, the strength of these roles and the extent of agreement amongst the three participant groups; the individuals living with dementia, their informal carers and formal carers.

- Chapter Five provides a detailed discussion, with an interpretation and evaluation of the results obtained from the Adapted-SIDQ with particular reference to the current literature on self-identity in dementia and dementia care. It also details a discussion of the feasibility of the Adapted-SIDQ, outlining the adaptability and acceptability of the questionnaire, as well as its implementation, including barriers and facilitators in relation to recruitment and data collection. Consideration is given to integration and further expansion of the Adapted-SIDQ. Limitations of the study, including overestimation of all participants' willingness to contribute, particularly informal carers, incurred time delays due to the multi-informant design of this tool. Details of ethical challenges, including application processes, research engagement and capacity to consent for this study will be considered. This chapter summarises the findings to provide implications for self-identity theory, for dementia care nursing, nursing leadership and for further areas of future research focus.

- Chapter Six provides a reflective account summarising my doctoral journey, culminating in the further development of my professional identity within dementia care nursing, academic study and professional leadership.

1.3 Introduction to dementia

In Germany in 1906, Dr Alois Alzheimer presented a scientific paper describing a fifty-one year old woman (Auguste Deter) with progressive memory loss, disorientation to time and place, hallucinations and an anxious, labile mood. She reported that she had "lost herself" (Miller, 2014), with her symptoms described as the "Disease of Forgetfulness". At post mortem, neurofibrillary tangles and neuritic plaques were identified in the brain and later identified as the condition Alzheimer's disease. However, today, dementia is now commonly used to describe a range of symptoms including, and which resemble, Alzheimer's disease irrespective of the cause of the illness. A definition provided by the ICD-10 Classification of Diseases (National Institute for Clinical Excellence/Social Care Institute for Excellence, 2007, p.67) states dementia is;

"*a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation*".

1.4 Prevalence of dementia

Worldwide prevalence figures estimate 47.5 million people live with dementia, and this number is expected to double to 75.6 million by 2030 and treble to 135.5 million by 2050 (World Health Organisation, 2016). An estimated 850,000 people in the United Kingdom currently live with dementia (Alzheimer's Society, 2013) with a suggested 1.3% of the United Kingdom population or one in every 14 of those aged 65 years and over having a form of dementia.

1.5 Types and frequency of dementia

In the United Kingdom, Alzheimer's disease (AD) accounts for 60% of all dementia cases, with cerebrovascular disease, or vascular dementia (VaD), for approximately 15-20%. Other conditions affecting the brain include Dementia with Lewy Bodies (DLB, 15%), frontotemporal dementia (also called frontal lobe dementia or Pick's disease), and Creutzfeldt-Jakob disease, accounting for 5% of the remaining diagnoses. In addition, dementia is associated with conditions such as Korsakoff's Syndrome, Parkinson's disease, Multiple-Sclerosis or Huntington's disease, and in other conditions, primarily or secondarily, affecting the brain (Alzheimer's Association, nd).

1.6 Progression and prognosis

Wattis and Curran (2006) state the progression and prognosis of dementia varies according to type. In AD distinct stages can be seen, from mild to advanced, with progressive deterioration in memory, language and functioning in day to day activities resulting in full dependence for cognitive, functional and psychological support. Approximate life expectancy for individual with AD is eight to ten years,

for VaD, five years and DLB, six to twelve years. Dementia can contribute to, but is the unlikely cause of death, with complications that arise from dementia such as pneumonia, and other associated physical illnesses or conditions (respiratory disease, heart disease, stroke or cancer) being the primary cause of death (Alzheimer's Society, 2016).

1.7 Diagnosis of dementia

In the United Kingdom, initial assessment of dementia is usually conducted through primary care services, with referral to specialist services such as memory clinics where an assessment by a specialist practitioner, psychologist or consultant psychiatrist aims to establish a diagnosis of dementia. The process of diagnosis requires a multi-dimensional approach, and may include the following; a comprehensive history of the presenting complaint(s), personal and family history, medical history (including blood tests to rule out physical causes of suspected impairment), personality review, and social circumstances. Cognitive testing using a validated tool such as the Mini Mental State Examination (MMSE, Folstein, Folstein and McHugh, 1975) or Addenbrooke's Cognitive Examination (Mioshi et al., 2006) is used to determine presence of cognitive impairment. Scanning, such as computerised tomography (CT) scan, specificity scanning such as single-photon emission computed tomography (SPECT), positron emission tomography (PET) or fludeoxyglucose (FDG-PET) may be included as an aid to diagnosis and subsequent decision-making for treatment interventions. There is no cure and no treatment that slows or stops the progression of dementia.

1.8 Treating symptoms of dementia

Treatment of dementia depends upon the cause of dementia as determined through assessment. If pharmacological treatment of the cognitive symptoms of Alzheimer's disease (impairment in language, praxis, organisational skills or attention and judgement) is indicated, acetylcholinesterase inhibiting drugs are used. There are three acetylcholinesterase inhibitors recommended by the National Institute of Clinical Excellence (NICE) in the United Kingdom (Department of Health, 2011, updated May 2016) and licensed to treat Alzheimer's disease; donepezil, rivastigmine and galantamine. They work by inhibiting the acetylcholinesterase enzyme from breaking down acetylcholine, thereby increasing both the level and duration of action of the neurotransmitter acetylcholine aiding communication between the nerve cells. This ensures signals from the brain are being sent and received, thus providing symptomatic treatment of the cognitive symptoms experienced in dementia. Memantine is used in moderate Alzheimer's disease for patients unable to tolerate acetylcholinesterase inhibitors. These medications are not a cure for the disease, but they can improve or alleviate symptoms. Approximately 30-50% of patients will derive some cognitive benefit from the medication (Wattis and Curran, 2006). Benefits could include improvements in communication, thought processes, problem solving, memory or functional ability. However, for some, benefits are small, and particularly at higher doses can include unpleasant side effects such as insomnia, nausea, dizziness and muscle cramps.

1.8.1 Mood disorders within dementia

Prevalence of depression in dementia ranges between 8-30% (Curran and Loi, 2012) and undiagnosed depression in dementia is common. Undiagnosed and untreated depression can exacerbate cognitive and functional decline (Wattis and Curran, 2006), increase behavioural disturbance, cause earlier admission to residential or nursing homes, and increase mortality in individuals with dementia. Depression in dementia is linked to several factors including coping with diagnosis, bereavement, loneliness, or financial distress, and treatment includes psychosocial interventions as first line treatment, but antidepressant therapy may be indicated.

Frazer, Christensen and Griffiths (2005) examined the effectiveness of treatments for depression in older people, and concluded that the treatments with the best evidence of effectiveness were; antidepressants, electroconvulsive therapy, cognitive behaviour therapy, psychodynamic psychotherapy, reminiscence therapy, problem-solving therapy, bibliotherapy (for mild to moderate depression) and exercise.

1.8.2 Behavioural and Psychological Symptoms in Dementia (BPSD)

BPSD are recognisable, understandable and treatable according to the International Psychogeriatric Association (2012). Behavioural symptoms include physical aggression, screaming, restlessness, agitation, sexual disinhibition, hoarding, cursing or shadowing. In contrast, psychological symptoms include anxiety, depressed mood, hallucinations and delusions. The individual maybe trying to communicate to those around them in a manner they know will elicit a response, regardless of whether that is positive or negative behaviour. BPSD have

been identified as a factor in threatening self-identity, and causing erosion of preservation of selfhood.

It is estimated that up to 90% of patients with dementia experience some form of BPSD over the course of their illness (Cerejeira, Lagarto and Mukaetova-Ladinska, 2012) which can be numerous, repeated or persistent. They can be transient in nature, exacerbated through physical illness or delirium, become more frequent, severe and complex in nature, or reduce to mild behavioural disturbance and disappear altogether. The pathway and prognosis of dementia when BPSD are involved is unclear, and individual outcomes are dependent upon the treatment offered, response to treatment and non-pharmacological approaches used.

In attempts to identify the psychological contributors to BPSD, including aspects of self-representation and self-reflection, links have been suggested between a neurological deterioration of the frontal lobes and subsequent symptoms such as depression or psychosis. However, the International Psychogeriatric Association (2012) state limiting causes to biological explanations fails to recognise other contributory factors, such as an individual's premorbid personality and identity, which could be involved. Whatever the cause, however, there is consensus that BPSD have a potential negative impact on the individual's identity (Feast et al., 2016).

1.8.3 Non-pharmacological treatment interventions

There are a range of non-pharmacological interventions for individuals with dementia such as; behavioural therapy, validation therapy, reality orientation, reminiscence therapy and life history work and cognitive stimulation therapy.

Psychological therapies do not prevent or delay progression of the disease, but they can provide benefit for the individual through symptom management. Aims of therapy include; improving cognition, improving the person's ability to function and maintain independence, reducing distress and mood disturbance, enhancing an individual's mental well-being and includes attempts to preserve self-identity, which is potentially at risk as the illness progresses (Woods, nd).

1.9 Dementia and carers

Two thirds of people with dementia live at home supported by informal carers, who are unpaid for their role in providing care. The definition of an informal carer is "*those who look after family members, partners or friends in need of help because they are ill, frail or have a disability*" (Social Care Institute of Excellence, 2013, Para 7).

Primarily it is a husband or wife that takes on the carer role (Quinn, Clare and Woods, 2010). Traditionally, if the individual with dementia is widowed or there is no life partner, it is often an adult child who takes on the responsibility, with evidence suggesting there is a greater expectation on daughters to provide this care (Gatz, Bengtson and Blum, 1990 and Armstrong and Armstrong, 2004). The Alzheimer's Association (2014) states that women are more than two and a half times more likely than men to provide intensive 24-hour care for people with dementia, and 20% of these women reduce their working hours to part-time.

Approximately one-third of people with dementia in the United Kingdom live alone (Mirando-Costillo, Woods and Orrell, 2010) with a close friend or neighbour adopting the role of carer. However, circumstances such the death of spouses,

family or friends can mean the individual living with dementia faces the illness on their own with no input from relatives or friends.

Reasons for adopting the caring role include love and affection, social norms for filial responsibility and feelings of guilt, or cultural expectation (Ward-Griffin, Oudshoorn, Clark and Bol, 2007). Caring for someone with dementia is often viewed negatively, although Svanberg, Spector and Stott (2011) document positive aspects, such as altruism, an increased feeling of fulfilment or a desire to reciprocate past support. However, a crisis in care may arise where the burden on the care giver exceeds the support which is required.

1.9.1 Support for carers

Carer support can be emotional or practical in nature, and includes; family and friends, social media forums, charities such as the Alzheimer's Society, memory services, post-diagnostic support groups, support workers, Community Psychiatric Nurses or social services.

The Care Act (Department of Health, 2014) provides guidance, information and advice on availability of support services, including how social care needs are assessed, met and paid for. It aims to ensure that any assessments for those to be cared for and those who provide the care are conducted in a simplified, consolidated manner to minimise ambiguity.

Crisis in care provision may arise from the emergence, severity or accumulation of behaviour related symptoms in dementia, care giver exhaustion or carer illness (Vroomen, Bosmans, Van Hout and de Rooij, 2013). Support for critical situations is provided through primary (GP) and secondary (Mental Health Intermediate

Care, Crisis Intervention or Community Mental Health Teams)care, and emergency services such as Accident and Emergency if there is a suspected physical cause for the change in presentation. Support may also be available through social care, with access to respite in nursing or residential care, if available, which can help manage the crisis.

Depending upon the severity of the situation and the outcome of a community review, a period of assessment and treatment in a specialist in-patient hospital may be recommended by Older Persons Mental Health (OPMH) services. The National Dementia Strategy (Department of Health, 2009a) states that avoiding institutionalisation is in the best interests of the person with dementia, but admission may be the only possible option to assess and treat symptoms or deterioration in mental and physical well-being, and determine a future care pathway with the individual with dementia.

1.9.2 Formal carers of individuals with dementia

A formal caregiver is a person contractually employed within health or social care to provide care in many different environments including home or community settings, such as residential or nursing homes, and private or NHS acute or psychiatric hospitals. Formal carers for older adults encompass all disciplines, including social workers, occupational therapists, physiotherapists, HCSW (Health Care Support Worker) or Registered Nurses (RN). According to the National Dementia Strategy (Department of Health, 2009a) all formal carers are required to receive training in dementia care.

Particularly, formal nursing staff should be selected based upon relevant values and attitudes required to work with people with dementia, including compassion,

sincerity, empathy and respect to work with and empower individuals living with dementia (Royal College of Nursing, 2015), and guidance is available which reflects this need for an integrated, inclusive approach.

The critical role nursing leadership has in providing and sustaining high quality dementia care is well documented (Morgan et al., 2005, Rokstead et al., 2013 and Jeon et al. 2014). There is a need for providing a clear nursing vision for person centred care, active role modelling, support, guidance, mentoring and empowering staff for professional development processes.

1.10 Nursing leadership and its importance for nursing practice within dementia care

In 2013 The Francis Inquiry report was published which examined the failings in care at Mid-Staffordshire NHS Foundation Trust between 2005 and 2009. The report made 290 recommendations, including: openness and transparency throughout the healthcare system (including a statutory duty of candour), fundamental standards for healthcare providers and an emphasis on compassionate caring and committed care. A recurrent theme throughout the report was the need for stronger healthcare leadership.

Nursing is a dynamic and challenging profession requiring engaging and inspiring role models and leaders. In today's ever changing and demanding healthcare environment, identifying and developing nurse leaders is one of the greatest questions faced by the nursing profession. However, the concept of leadership is complex due to its multi-dimensional aspects; research within the past 20 years demonstrates that although it is one of the most studied concepts, identifying one

universally accepted definition or theory of leadership is disputed (Saeed et al., 2014).

There is, however, increasing clarity with regards to what constitutes nursing leadership, and how it might differ from management. Cummings (2008) found that perceptions of nursing leadership were different from general leadership because it placed a greater emphasis on nurses taking responsibility for and improving and influencing the practice environment.

Cummings (2008) demonstrated that research into nursing leadership falls into two main areas; studies of the practices and actions of nursing leaders including the impact of different health care settings, and the effects of different educational backgrounds of nurse leaders. The conclusions from the systematic review by Cummings (2008) suggested that leadership from nurses can be developed by a stronger emphasis being placed on future leadership styles modelled on those which have demonstrated as being seen to be successful in the workplace such as transformational leadership (McIntosh and Tolson, 2008). Several studies highlighted personal characteristics which were deemed to promote leadership qualities, such as openness and the motivation to lead others (Jackson, 2009, Brady, 2010 and Sanderson, 2011). They demonstrated that leadership was perceived to be less effective when leaders had less contact with those delivering care, highlighting the importance of nurses on the ward and within community settings to also be effective leaders (Richardson, 2010 and MacPhee, 2012).

The emphasis which has been placed on interpersonal skills and relationships between healthcare workers is strongly suggestive that this is an important leadership skill (Malloy, 2010). A recent review of the role of emotional intelligence

(the capacity to be aware of, control, and express one's emotions, and to handle interpersonal relationships judiciously and empathetically) and nursing leadership, highlights the need for these skills in effective leaders and has been shown to be highly influential on health care cultures (Hutchinson, 2012).

The Francis Inquiry (West et al., 2014) stressed the importance of strong nurse leadership and the concept of from "ward to board" was introduced in order to drive up standards of excellence, support an open organisational culture and deliver high quality and safe patient care (Matchell, Gough and Steward, 2009, p.5). Although the NHS currently faces many challenges such as financial constraints and a growing elderly population, leadership cannot be viewed as an optional role, as the importance of effective leadership to the provision of good quality care is firmly established.

For me, leadership is about being adaptable and making a difference to those I encounter in my day to day practice by thinking differently. One of the key leadership challenges I face within my profession is the ability to be able to deal with the pressures of today and to be part of the vision of tomorrow with regard to dementia care. Nursing leadership needs to be cultivating an understanding with the nurse at the bedside and to help them take an idea and grow it into an improvement or research project. The value framework (NHS England, 2016) derived from the 6C's (care, compassion, competence, commitment, communication and courage) and the Triangle of Care (Royal College of Nursing, 2013) enables nurses to work in partnership with patients, colleagues and across organisational boundaries, with reciprocal learning towards the best solutions for patients.

1.10.1 The Triangle of Care

One attempt to describe the tri-directional communication and impact of dementia on the individual, informal carer and formal carer is the Royal College of Nursing (RCN, 2013) document '*The Triangle of Care. Carers Included: A Guide to Best Practice for Dementia Care*' (Figure 1).

This is a practice guideline outlining the standards carers can expect when an individual with dementia requires health and social care.
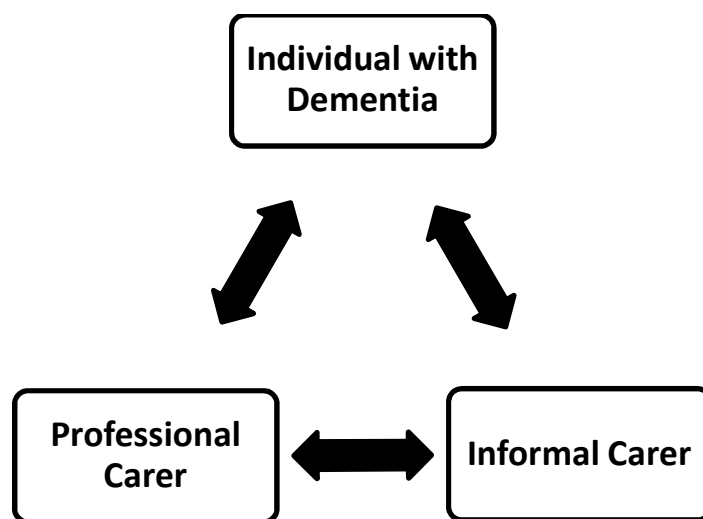
Figure 1 Triangle of Care (RCN, 2013)

The six key standards state that: (i) the essential role carers play are identified at first contact or as soon as possible thereafter, (ii) staff are 'carer aware' and trained in engagement strategies, (iii) policy and practice protocols regarding confidentiality and sharing information are in place, (iv) defined post(s) responsible for carers are in place, (v) a carer introduction to the service and staff is available, with a relevant range of information across the care pathway, (vi) a range of carer support services are available (RCN, 2013, p.3).

The toolkit contains a self-assessment proforma to evaluate whether the six key standards are being met, including a collaborative team approach to assessment, treatment, care, and discharge planning. It ensures informal carers are appreciated as partners in care, ensuring positive engagement, recognising the essential role they have in providing care, with the aim of achieving better outcomes for the person living with dementia. It emphasises the importance of tri-directional communication between the three groups; individual with dementia and informal carer, individual with dementia and formal carer, and informal carer and formal carer.

1.11 Approaches to dementia care - Person centred care

Person centred care is central to several policy documents associated with older adults, dementia and dementia care, including the National Institute of Clinical Excellence (NICE) guidance on Dementia (Department of Health, 2006, updated 2016), the National Dementia Strategy (Department of Health, 2009a), Dignity Challenge (Department of Health, 2009c) and The Dementia Challenge (Department of Health, 2012).

Professor Tom Kitwood was one of the originators to the development of a person centred philosophy when applied to dementia care. He defined personhood as;

"A standing or status bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect and trust" (Kitwood, 1997, p.8).

In the mid-1980's, Kitwood (1997, p.4) described the "*demeaning and disregarded*" manner those with dementia were treated with. He challenged the prevailing medical model, the "*standard paradigm*", with its therapeutic nihilism and dominant focus on psychiatry and neuropathology related to dementia.

Kitwood and Bredin (1992a and 1992b) proposed an alternative approach, explaining that dementia is an equation resulting from the combination of five factors: personality, biography, health, neurological impairment and social psychology. Therefore, dementia = P + B + H + NI + SP. They believed that personality (P) was not the sum of traits but rather a repertoire of resources accumulated throughout life closely related to opportunities and experiences. These include an individual's biography (B) which, without it, would be difficult to understand the phenomenon of dementia (particularly its effect on an individual) without the persons' sense of their self and life history. Health (H) was also a vital component, as dementia should not be viewed in isolation, but that the persons' physical health needs are given equal consideration, and how loss of mobility or sensory impairments can affect the individual's abilities for social interaction. The repertoire of resources emphasise that dementia care depends not only on the physical changes through neurological impairments (NI), but also their social psychology (SP).

The quality of person centred care is dependent on the recognition of the role social interaction between informal and formal carers has on those with dementia. Through understanding these interactions and the needs of individuals with dementia, they can be supported to live well with dementia.

Central to the approach is a needs-led model of dementia care (Kitwood, 1997, Figure 2), which claims those with dementia have six psychological needs (comfort, attachment, inclusion, love, occupation and identity) which require support, and are fundamental to ensuring the well-being of those with dementia is maintained.
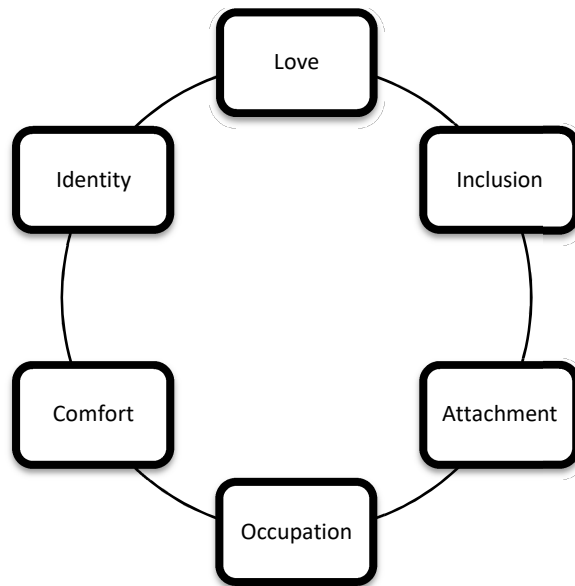
Figure 2 Six Psychological Needs (Kitwood, 1997)

The individuals' sense of identity is of paramount importance as it provides a "*sense of continuity with the past, a narrative*" (Kitwood, 1997, p.83). He outlined how the standard paradigm of dementia care, where links to the past and identity were removed through institutionalisation, eroded essential aspects of the individual's sense of self. He proposed through the use of the person centred model, would allow self-identity to be maintained. This was achieved by ensuring those individuals with dementia had secure attachments to other persons, were actively engaged, had meaningful occupation in their lives and were included in society.

Kitwood (1997) developed Dementia Care Mapping (DCM), an observational tool which aims to evaluate the extent to which the person centred approach has been implemented in a formal care setting for those people with dementia. The focus is on the individual living with dementia and their subjective experiences. It is a well-validated tool (Brooker and Surr, 2006) and, following revisions and updates, for the past 20 years has effectively been used in research studies involving those with dementia (Kelly, 2007, Sloane et al., 2007, Chenoweth et al., 2009 and Surr et al, 2016b).

The person centred philosophy is not beyond criticism, but there is a well-established link between the approach and positive outcomes for those with dementia. Reports of positive change to clinical practice have been made following person centred care principles being adopted in different areas of dementia care, such as cognitive assessment prior to diagnosis of dementia (Bush, 2007), best practice guidelines for implementing choice into everyday practices (Twigg, 2009), and the benefits of continued sensory stimulation and occupational activity (Perrin, 1997). Chenoweth et al. (2009) published findings of a cluster-randomised trial to provide evidence of a comparison between person centred care, dementia care mapping and 'usual' care practices. Their primary conclusion was that the implementation of person centred care and dementia care mapping can reduce agitation levels and improve well-being within residential settings.

Bartlett and O'Connor (2007) commented that Kitwood's theory on personhood, despite documented improvements it had made in raising the status of those with dementia, was limited in scope and impact. They proposed an integration of personhood and the concept of citizenship to widen the lens through which the complexities and experience of dementia could be accounted for.

However, Kitwood's influential philosophical and theoretical themes relating to person centred care have attempted to address concerns of permanence or political kudos with its inclusion and profound influence in many policy papers as described above.

Across health and social care, delivery by healthcare professions and perhaps particularly for the nursing profession, there is no doubt that the philosophy of person centred care has made a "*powerful contribution*" (Innes, 2003, p.156), the values of which strongly provides a basis for the 6 Cs within the nursing profession (NHS England, 2016). The person-centred approach to nursing ensures that there is a focus on the individual's personal needs, wants, desires and goals so that they become central to the care and nursing process.

Kitwood (1993, p.51) stated that through the implementation of a theory towards dementia care, he could be "*cautiously optimistic conclusions are reached about the possibilities for enabling dementia sufferers to remain in a state of relative well-being*" rather than the negativity that surrounded a person once diagnosed with an illness that was, and still is, described as a "*living death*" (Hill, 2008).

1.12 Chapter One Summary

Chapter One has provided an overview, context and structure for this study, with an introduction to contemporary thinking on dementia and dementia care and treatment, in addition to a description of the impact of dementia on the individual, their relatives and their formal carers.

Chapter Two will now provide an overview of the theoretical concepts of self-identity to provide the context for the investigation that follows, outlining the literature review strategy to explore measurement of self-identity within dementia care.

Chapter Two - SELF, SELF-IDENTITY IN DEMENTIA AND ITS MEASUREMENT

Chapter Two provides an overview of the theoretical concepts of self-identity to provide the context for the investigation that follows. The chapter explores contemporary definitions and explanations of self-identity, psychological and sociological perspectives, self-identity in illness and its application to dementia care.

An outline of the literature review strategy conducted to describe both dimensions of and measurement of self-identity within dementia care will be provided. The qualitative studies that aim to describe self-identity dimensions will be outlined, and the quantitative measures and tools that have been developed or utilised discussed, exploring the strengths and limitations of the approaches used.

Lastly, this chapter will provide an outline of the rationale for the research approach, namely a feasibility study, and the choice of measurement tool and subsequent adaptation of the Self-Identity in Dementia Questionnaire (SIDQ). The chapter will conclude with the development of the research questions, aims and objectives.

2.1 Definition of self-identity

The concept of self-identity has interested philosophers, psychologists and academics for centuries. In the late nineteenth century, William James (1890) discussed the nature of self and its complexities, and others have sought to refine and expand upon the concept and its multi-dimensionality ever since (Gallagher, 2000). Strauss (1959, p.9) stated *"identity as a concept is fully as elusive as is everyone's sense of his own personal identity"*.

David Hume (2000, p.18) is the most influential critic of the notion of *"self"*. Hume, a philosopher rejected the notion of identity over time. There are no *"persons"* that continue to exist over time; there are "merely impressions" of the individual, where they are able to comprehend, according to Hume, "all our more lively perceptions, when we hear, or see, or feel, or love, or hate, or desire, or will." This idea can be formulated as the following argument: (1) All ideas are ultimately derived from impressions, (2) So, the idea of a persisting *"self"* is ultimately derived from impressions, (3) But, no impression is a persisting thing, (4) Therefore, there cannot be any persisting idea of *"self."* In short, because the *"self"* must be constant, persistent and stable, yet all knowledge is derived from impressions, which are transient, non-persisting, variable things, it follows the premise that we do not really have knowledge of a *"self"*. Identity, for Hume (2000) is the idea of an object that is uninterrupted and invariable over time. Hume later acknowledged that he made *"considerable mistakes"* in his thinking related to self and identity and went on to amend his original works (Blomfield, 2008). In her detailed critique of Hume's work, Blomfield (2008) explores Hume's reinterpretation of his ideas on self-identity, and concluded that his change in direction appeared to arise from his frustrations as to the simple nature by which attempts were being made to explain

the self and identity. Hume had stated that all our distinct perceptions are distinct existences yet Blomfield (2008) argues perceptions do "form a whole" – they form a bundle to which we attribute simplicity and identity – so they must be "connected together". Hume's (2008, p. 173) negative theoretical stance related to self and subsequent "second thoughts" informed further exploration into the notion of self which continues to add to our understanding to and knowledge of self.

Adopting one definition of self-identity is further complicated with interchangeable terms such as self, self-awareness, self-concept, self-consciousness and selfhood being applied (Fazio, 2008), whether such a definition can be applied across different societies or cultures, within and across disciplines, and debates that take place about whether the "self" is a single or plural concept (Leary and Tangney 2012).

Lemme (1999) provides comprehensive background and theory on adult development, investigating adolescence, adulthood and older adulthood, and the diverse perspectives of self-identity in each stage of life. Thorough examination of the nature and influences of age, gender, cohort, race, ethnicity, socioeconomic status, and culture on development resulted in Lemme (1999) contributing to theoretical foundations of life span development, including identity. Identity from this perspective is understood as a disposition of personality features acquired mostly during childhood and, once integrated, remaining unchanged over the lifespan (Sokefeld, 1999). However, this approach has been disputed as societal influences can alter a person's sense of self-identity over time. Erikson (1956) adds to the debate further, stating that self-identity *expresses such a mutual relation in that it connotes both a persistent sameness within oneself (self-*

sameness) and a persistent sharing of some kind of essential characteristics with others" (Erikson 1956, Introduction, Para. 2).

A proposed definition of self states "*the self is the knowledge, feelings, and attitudes we have about our own being as unique, functioning individuals*" from Lemme (1999). Whilst this definition is simplistic, other definitions have reflected the earlier work of William James, providing a detailed distinction between "I" and "me" yet focusing on the interplay between the two concepts, such as Mead (1934). However, Tejera (2001, p. 59) states "a *complete fusion of the 'I' and the 'me' may not be a good thing...it is a dynamic sort of balance between the 'I' and the 'me' that is required*".

2.2 Psychological perspectives on self-identity

Developmental psychologists such as Harter (1999) believe that the self is dependent upon an individual's recall of specific personal experiences. This viewpoint contributes to the notion that self-identity can be lost within dementia, arguing if the individual is cognitively impaired and cannot recall enough to provide a narrative of their memories, there is an unbecoming of the self (Fontana and Smith, 1989) and the self is therefore lost.

For Erikson (1997), identity maintains an individual's inner accord with the ideals and aspirations of external forces such as social groups. He proposed various syntonic versus dystonic elements across the life span, ranging from child development through adulthood and aging. Within the eighth stage of the life cycle in later life, old age presents the ego with a challenge to identity; integrity versus despair. Joan Erikson proposed a ninth stage of development, revisiting the previous eight stages in later life, with a sense of self expanding to include "*a*

wider range of interrelated others" (J. Erikson, in Erikson, 1997, p.124). The premise is that the ego's strength is diminished through cognitive, personality and behavioural changes within dementia, with successful development of the personality depending on individuals overcoming these crises for a successful resolution to the threats to identity.

2.3 Sociological perspectives of self-identity

Erikson (1997) acknowledged the contribution social interaction has to the development, influence and support of self-identity. The influential works of Mead (1934) focused on the self as a process with two phases: the "I" who is the inner, subjective self, and the "me", the social self. According to this view, the line of separation between the self and the body is found in the social organisation within which the self and identity arise. Symbolic Interactionist, Blumer (1966), an advocate of Mead's work, viewed the individual as a social construction through interactions with others. He believed that individuals create their own social reality through collective and individual action and Bruner (1990, p.34) stated "*it is culture, not biology that shapes human life and the human mind that gives meaning to action…*", whilst Kitwood (1997) stressed the impact of interaction and influence of others on the well-being of those with dementia. This was emphasised further by Swann, William and Bosson (2008, p.448), who claimed "*the survival of people's identities rests not only in their own hands but in the hands of others*".

Bruner (1990) maintains that use of language, communication and interaction with the social world maintains our sense of self, with an emphasis on the importance of narratives and roles people adopt throughout the life span and the interaction that arises from those roles (Cohen-Mansfield et al., 2006a). As with the

psychologist Harter (1999), Bruner (1990) outlines that being able to provide a narrative of ourselves is a fundamental aspect of understanding who we are, affirming that story-telling is a universally adopted phenomena, and a process whereby we organise experiences and memories in a culturally accepted form to be shared with others. This narrative identity (McAdams, 2001) maintains that individuals form an identity by integrating their life experiences into an evolving story of the self, which provides them with a sense of unity and purpose in life. The life narrative combines an individual's past, perceived present, and thoughts about the future. Sacks (1985, p.110) adds that an individual "*constructs and lives a "narrative"... this narrative is us, our identities*". However, Bruner (1990) does not question whether the self-narrative provided should be accurate or realistic, inferring that through the cognitive, personality and behavioural changes that occur through dementia, the maintenance of a narrative of self is still possible.

Sabat and Harre (1992) outlined that self can be expressed through public discourse (conversation, language and behaviour) and can be identified in three different ways combining to form a constructionist framework to describe self-identity; Self-1, Self -2 and Self-3.

Self-1, or the self of personal identity can be confirmed through a person's use of first person references to self (I, me, myself, mine and my). Through the use of these terms, we are able to express our personal identity and Sabat and Harre (1992) stated that we take responsibility for our actions as well as locate for others feelings and experiences that are expressed in conversation.

Sabat and Harre (1992) maintain that Self-2 is the socially constructed self, and is "*comprised of a persons' physical and mental attributes and beliefs about those attributes*" (Sabat, 2002, p. 27) such as self-worth connected to intellect. This social self is developed over time through the multiple distinct identities that emerge throughout an individual's life as they interact with others (for example, mother, father, school teacher, or builder) and the adoption of various social roles. However, for an individual to acquire a social role requires acknowledgement from others that the individual possesses that role. Self-2 "depends for their existence upon the cooperation of others in the social context" (Sabat and Harre, p. 452-453).

Self-3 is the personae that demonstrate an individual's social and public self. These are constructed in the variety of situations in which we live our lives, with each persona inducing a specific pattern of behaviour that is distinct from any other. This form of self, as with Self-2, depends upon others for the social personae to be. Sabat (2002) explains that is would be difficult for an individual to "construct" the Self-3 of the role of "dedicated teacher" if the students did not recognise them as their teacher. Of the three types of self, Self-3 is the most vulnerable in that if there is no one to validate the construction of a role, or the social world views them in a negative manner such as through illness, there is the potential for a loss of Self-3. Sabat and Harre (1992) assert that individuals living with dementia retain aspects of self associated with their personal identities (Self-1), but social identity (Self-2 and Self-3) can be lost through a lack of validation and how others view and interact with them.

The social constructionist model is based upon the belief that language is of fundamental importance in the creation of an individual's social state, and Caddell and Clare (2010) report that the manner by which language is acquired can influence thought processes and experience. Therefore, the self can be constructed in and through social interactions with others. What this theory addresses less successfully is how those individuals living with severe speech, language or communication difficulties can confirm their identity, yet researchers who have worked with individuals in the advanced staged of dementia have used the social constructionist framework to explore self identity in those living with Alzheimer's disease (Tappen, Williams, Fishman and Touhy 1999).

Herskovits (1995) claims that there is no obvious way to adjudicate between competing approaches and definitions. However, for the purpose of this research, the concept of self-identity will be defined through the individual's awareness of a first person perspective, a sense of self-concept where their self ascends from their beliefs about themselves and the responses of others, similar to the descriptions of self-identity as proposed by Lemme (1999). This definition allows for aspects of self-identity to be communicated and measured, as well as encompassing the core principles of the person centred care approach to dementia care in viewing the individual as unique and valuing this throughout all interactions, and is therefore be appropriate to adopt for this research study.

2.4 Summary of self identity theoretical perspectives

To say there is a "*self*" that persists throughout one's life is to say that there is something about a person that survives from birth, through until death that makes a person the same person over time. Yet one may question how can anything

identified as a "*self*" can persist through the many changes that happens throughout living one's life? When we consider that our physical bodies change as we age; our beliefs, desires, interests change over time and our personality changes and develop depending on the lives we have lived and experiences encountered. It would therefore seem almost impossible to explain the *"self"* deriving from any one perspective to explain the development, maintenance and changes through the life span. It would be expected that the study of the self would be able to answer these questions, yet the variety of definitions and psychological and sociological perspectives provided on self (Sections 2.1-2.3) have demonstrated the breadth of the topic, yet they all contribute to contradictory arguments surrounding the concept. As identified, there are a number of key arguments related to self and self-identity; the self and identity do not exist (Hume, 2000), the self does exists but other interchangeable terms are used to describe it such as self-knowledge or self-consciousness (Fazio, 2008), it has been described as a single and a plural entity, and debate ensues surrounding whether there just one self or multiple selves.

Oysterman, Elmore and Smith (2012, p. 75) summarise stating "*theories converge in assuming that self, self-concept and identity come from somewhere, are stored in memory, and matter*", which all relates to their importance.

Leary and Tangney (2012) state that there have been criticisms of theories related to self, viewing the concept in a disembodied and decontextualised manner, losing both the psychosocial and personal nature of the self. According to Leary and Tangney (2012) self and identity theories converge in the belief that self and identity are mental constructs and represented in memory, but these statements arise from research conducted in childhood and inferences are made as the brain

and memory changes either though the aging process or illness such as dementia. The theories of Blumer (1966), Bruner (1990) and Harter (1999) hold assumptions of stability in that once an identity is developed it would be difficult to change. These assumptions do not address what happens to an individual's identity when they encounter change, such as illness and the need for a more fluid understanding of self as the self protects itself and adjusting when the conditions of life require it (Swann 1983).

Researchers and academics have made fundamental steps to illuminate what the self and self-identity mean, and Leary and Tangney (2012) claim that the future of research into self will largely depend upon how successfully theoretical advances are able to link together specific threads of research that focus on self and identity.

2.5 Self-identity in illness

Although the self arises from internal beliefs about themselves and the responses of others, additional factors can adversely influence self-identity such as illness.

Illness refers to experiential aspects of a physical disorder which are shaped by cultural factors governing perception and explanation of the experience (Kleinman, Eisenberg and Good, 1978). According to Kelly and Millward (2004) there is a need to understand the reciprocal relationship between identity and illness; the self and identity can shape the way illness is perceived and responded to, and in turn illness can have an impact, either positive or negative, on the identity of a person. Illness can invoke changes both physically and psychologically, whilst having a drastic effect on an individual's sense of self, however it must also be noted there is a difference between acute illness and chronic illness. When encountering a

minor short-term acute illness, such as a respiratory tract infection or minor traumatic disorders such as back ache, adaptive behaviours are employed and there is a focus on immediate recovery as the illness may be self-limiting or require minimal treatment. However, with chronic illness (long-term conditions and progressive, terminal disease) the impact exerts greater consequences on the individual's sense of self, with a different perspective on recovery (Charmaz, 1983). There is an emphasis on learning and developing an understating of the illness, gaining control of it, reducing the impact of the illness on their lives and re-establishing a positive identity (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010).

The impact chronic disease has on self-identity provides valuable insights to the experience of illness. Studies such as those by Woods, Boot and Simpson (2010) focused on changes to identity through Multiple Sclerosis, Yanos, Roe and Lysaker (2010) reviewed self and recovery in mental illness, and Gillies and Johnson (2004) compared the experiences and identity changes between diagnoses of cancer and dementia. These studies identified that the subjective experience of illness on identity varies from person to person, with interpersonal and adaptive factors influencing the outcome for the individual experiencing the illness.

2.6 Self-identity in dementia

In a similar way, dementia can induce changes in self-identity, and identity can influence changes in dementia.

The traditional and prevailing perspective of dementia maintains that it is a threat to self-identity, characterised with multiple losses arising from cognitive decline,

worsening orientation, reasoning and communication abilities. The result is a stream of distressing experiences for the "sufferer" when misunderstanding or being misunderstood. These negative experiences are emphasised by publications of narratives such as McGowin (1993, p.124) who, with a diagnosis of early onset dementia, poignantly stated: "*my every molecule seems to scream out that I do, indeed, exist and that my existence must be valued by someone*". Sterin (2002) also commented on the lived experience of dementia in that she felt she was "*becoming invisible*" as her dementia progressed. Grant (1999, p.146), when describing her mother's illness, stated: "*the disease begins to turn its malign attention to the very heart of herself as she struggles to hold her identity together*", and the work of Matthews (2006, p. 163) further reflects this perspective, quoting carer experiences: "*he's not the man I married*" or "*she's not the mum I used to know*", when trying to make sense of, and cope with, dementia. Fontana and Smith (1989) go on to consider an unbecoming of the self through the progressive journey of dementia. Through interviews with ten people with dementia, four themes emerged which represented views on aspects of their current identities; whether dementia would alter their identities in the future, perceptions of how living with dementia had affected their relationship with friends and their relationship with family. Overall, there was little change with respect to their identity as a whole, but features of self were identified that were different than before the onset of dementia. Fontana and Smith (1989, p.379) concluded that "*participants were in a state of flux, experiencing both continuity and change in their sense of identity simultaneously*".

Through studies on self-identity in dementia, key themes also emerged related to self-identity in dementia, which include threats to self-identity, and protection and

preservation of self-identity in dementia. A brief overview to provide wider context and background to the complexities of investigating self-identity in dementia follows.

2.6.1 Threats to self-identity in dementia

Following a diagnosis of dementia, an individual needs to register, react and adapt to the cognitive and emotive changes induced. Unsuccessful adaptation results in interrelated coping mechanisms not being "activated" (Clare, 2003, p.1026) and there is a clear threat to the self-identity of the person with dementia. As the illness progresses, the symptoms experienced have the possibility to detract from the individual's identity.

Institutional or organisational values and beliefs may threaten self-identity, with rigid task orientated practices implemented. Kitwood (1997) described a Type A and Type B care setting. Type A is authoritarian, with a hierarchical structure and impersonal communication means, causing a high power differential not only between different grades of staff but between the staff and individuals in the care setting, resulting in a threat to the individual's self-identity. Low morale through poor organisational structures can contribute to stress and burn out (Norbergh, Helin, Dahl, Hellzén, and Asplund, 2006) and unintentional poor nursing practices.

An example from the Francis Report (2013, p. 66) highlighted the very real impact a Type A organisation and environment can have in nursing practice;

"The investigation has found evidence of poor leadership and management and of poor nursing care on Ward 3 … There is a strong view on the Ward that failings are due to the poor staffing levels and therefore excusable. The culture on the ward appears to allow for support of this view … Nobody at directorate/Trust level appears to have taken responsibility for monitoring/auditing to ensure that basic nursing standards/patient care needs are met … There appears to be a lack of commitment at the highest level in the Trust to tackle these problems".

The environmental features of the living conditions in Type A care settings act to restrict independence, choice and personalisation, and do not provide social contact, providing a considerable threat to self-identity in individuals with dementia. In contrast, the Type B setting ensures effective leadership and management through role modelling, two-way interpersonal communication between the care teams, a low power differential, and minimal status divisions between staff. The benefits to those with dementia potentially are: reduced stress, anxiety, aggression and disturbed behaviour, an improved patient experience, improved dignity, improved interaction between staff and patients, and improved patient outcomes and quality of life.

2.6.2 Protection and preservation of self-identity in dementia

Clare (2003) investigated threats to self in early onset dementia and the continuum of responses from those with dementia to adjust, cope and maintain aspects of self. Individuals with dementia protected themselves through normalising

situations to minimalise the challenges symptoms of dementia induced. Adjustment to the illness required reliance upon what they knew about themselves.

Beard (2004) used a multi-method study to establish the experiences of those with Alzheimer's disease in preserving their self-identity. Three themes emerged; "*defining moments*", "*to tell or not to tell*" and "*preservation*". The insights gathered from the first two themes were significant, but the third element, preservation, highlighted the strategies individuals employed "*to try and make sense of their worlds*" (Beard, 2004, p.424). In order to preserve identity, strategies were employed to minimise "exposure" of their difficulties through the illness such as unfamiliar social settings or tasks they were unaccustomed to. Similarly, avoiding awkward questions or conversations helped them to prevent difficult situations. Beard (2004) outlined the deliberate tactics used to ensure the self is actualised to preserve their social personae as the symptoms of dementia progress.

Surr (2006) reported that preservation of self was achieved through the adoption of positive social roles related to being part of a family, work, or being able to care for others and being cared for. Further evidence from Beard, Knauss and Moyer (2009) highlighted coping mechanisms of those with dementia, managing the illness as a disability and integrating this mind set into their existing identities. The participants reported that using aids such as cognitive reminders, modifying their environments, and assistance acceptance of their symptoms from others were all central to working with the illness and enriching their lives. Beard, Knauss and Moyer (2009) claimed that by reframing dementia into a "disability", those with the illness felt more empowered with regard to the maintenance of their identity.

A systematic review conducted by Caddell and Clare (2011) investigated interventions that would support the self-identity of individuals with dementia. Ten studies were identified which supported the self or identity with no outcome measure, those whereby interventions were theoretically linked to the self or identity and studies which supported the self and identity with specific outcome measures. The first group used art-based therapies, which preserved identity through self-expression and exploring positive coping mechanisms. The second group involved music-based therapeutic interventions and the individuals' responses to this. Group three had four diverse studies such as a four week residential therapy programme, life history sessions and life books to preserve personhood and strengthen self-identity throughout the progression of the illness, and a case study whereby biographical theatre was used to display important aspects of the individual's life around their home, which in turn was displayed on a touch screen computer to allow the individual to review life periods. Caddell and Clare (2011) found these studies were methodologically weak, with design flaws and incomplete data sets, with limited conclusions drawn as to the effectiveness of preservation of self-identity.

Adopting the definition proposed by Lemme (1999), it is recognised that self-identity can positively or negatively influence dementia, in the same way disease and disease progression can affect individuals living with dementia. Therefore knowing what a person's identity is, and perhaps measuring it in some way, might indicate what, if anything has changed over time, or the potential to identify environmental influences.

2.7 Self-identity, dementia and my personal philosophical stance

Despite the various theoretical perspectives proposed on self-identity, I have found a strong affinity not only with the work of Tom Kitwood (1997) as described in Section 1.10 whose philosophy has greatly influenced my clinical practice with my nursing interactions based upon the individual's six psychological needs (comfort, attachment, inclusion, love, occupation and identity), but also of the three types of self as proposed by Sabat and Harre (1992). Working within older persons mental health nursing has enabled me to identify with these three types of self (Self-1, Self-2 and Self-3) and utilising this framework with individuals as I described in the Preface of this thesis. Personal reflections and learning from my nursing practice have informed my interactions when working with individuals across the continuum of severity of dementia. A focus on the verbal and non verbal communication patterns of those living with dementia has enabled me to identify and acknowledge the use of first person references which communicate aspects of the individuals' identity. Skilled interpretation of this discourse can enhance their personal narrative thus validating and maintaining their identity. The underlying philosophy of the social constructionist approach provided a framework I could identify with, in that the self is not lost in those living with dementia – it is the challenge of us as nurses and carers to try and understand what is being communicated.

My philosophical approach is similarly influenced by the late Oliver Sacks (1985), a British neurologist, whose exploration of neurological and cognitive disorders provided great insights, bringing an understanding of the clinical science of the brain to a wide audience. Through his work he did not differentiate between those living with dementia and those not, and his stance on self-identity reflected mine in

that we are each strange and complex in our own ways, yet the journey travelled with the illness is as unique as we all are. He was the type of thinker whose writing induced thought, debate and introduced creative ideas, especially when applied to dementia care. His work on Music and Memory demonstrated a "reawakening" and bringing older adults "to life" throughout their illness which had detracted from their well-being. He stated musical perception, musical sensibility, emotion and memories associated with music can survive long after other forms of memory have disappeared. His work resonates with me and demonstrates how by using interaction to positively engage those living with dementia, a powerful narrative can be established which provides the individuals stories and therefore aspects of their identity. The underlying philosophy from my clinical practice and increased understanding of the impact of socially based communication, interaction and intervention on self-identity went onto influence the theoretical and research approach used for this research study and how to use the knowledge to attempt to find the answers to the research problem.

2.8 The research problem

Within my clinical practice as an acute psychiatric in-patient nurse, there was no tool or measure used to identify aspects of self-identity for those living with dementia. On admission to hospital individuals enter an unfamiliar and busy clinical environment with other people who may be presenting a variety of behavioural difficulties that induce fear and heightened anxiety. A plethora of different people (patients, staff, visitors) and experiences add to an already confused and disoriented individual. This over stimulation and potential lack of comprehension can cause severe distress, exacerbating any behaviour presented

prior to admission. With all these competing stimuli, the admission process could potentially contribute to the temporary or permanent erosion of the preservation of selfhood in people with dementia (Kitwood, 1997 and Chaudhury, 2008).

As a Senior Nurse leading and managing an in-patient psychiatric ward, I identified the potential to address this area of practice in order to improve the experience and well-being of those who entered our care environment.

Further evidence for the study arose from observations made when witnessing clinical practice of my nurses in that there was very little evidence base to the nursing interventions being implemented to support those living with dementia. Clinical supervision also identified minimal innovative or creative ideas or approaches to care, and little insight, knowledge or understanding related to how dementia impacts on an individual's sense of self from diagnosis to end of life care in the more advanced stages of the illness.

The aim of this study is to firstly identify a validated tool to measure self-identity in people with dementia and, once identified, conduct a feasibility study to evaluate the usefulness of the specific measure or tool to determine if dimensions of self-identity in dementia can be ascertained and measured when admitted into an acute psychiatric in-patient hospital.

2.9 Search methodology for measurement of self-identity in dementia

The original literature search was conducted between June and August 2012, with an updated review in September 2016, with both searches combined to inform the review.

2.9.1 Defining the literature search question

The acronym PICO (Patient/Population, Intervention, Comparison/Control, and Outcome) as described by Richardson, Wilson, Nishikawa and Hayward (1995) was used to develop a focused question for a systematic literature search. PICO was originally developed to facilitate the formulation of clinical queries for evidence-based practice, enabling process whereby questions relating to an investigation could be articulated with precision to maximise evidence retrieval related to the research question(s) being posed. Without a well-focused question, it can be challenging and time consuming to identify appropriate resources and relevant evidence (Schardt, Adams, Owens, Keitz and Fontelo, 2007). Table 1 demonstrates the application of PICO to this search strategy.

Table 1 Formalising the research question using the acronym PICO

Question Components			Search Terms and Synonyms
P	Patient or Population	Dementia	Dementia / Alzheimer's disease / Alzheimer disease / vascular dementia / frontal lobe dementia / cognitive impairment
I	Intervention	Measurement of self-identity	Identification / measurement / measurement tool / assessment tool of self-identity / identification / describe / determine / establish
C	Comparison or Control	N/a	N/a
O	Outcome	Quality of Life	Quality / quality of life / QoL / well-being / well-being / benefits / advantages / preservation / dimensions of self-identity

Population (types of participants):

The review question included patients with a confirmed diagnosis of a type of dementia, including Alzheimer's disease, vascular dementia, frontal lobe dementia, and other forms of dementia and cognitive impairment to potentially include diagnoses of mild cognitive impairment (MCI, with an increased risk of developing a dementia). The population would include those over the age of 50, to include those with early onset dementia (those younger than 65 years). The participants could be based in a community setting including their own home, residential or nursing homes, or a hospital setting.

Intervention:

This review focused on the methods of identification, measurement or assessment of aspects of self-identity, whether it is a new measure or a previously validated tool.

Comparison:

For this literature search there were no comparisons identified, and according to Sackett, Richardson, Rosenberg and Haynes (1997) a "good" literature search question does not always need a comparison or control to be valid. Comparison is an optional component in the PICO question, and it is possible to look at the intervention without exploring alternatives.

Outcomes:

It was planned to explore potential patient-related outcomes, such as whether the tool was able to measure aspects of self-identity in those with dementia and how the self-identity information was collected and used to contribute to quality of life

(QoL) or well-being measured by means of a validated scale, including patient's self-assessment or self-report questionnaires such as the Quality of Life in Alzheimer's Disease (QoL-AD).The review question being asked was:

*"In patients with a diagnosis of dementia **(population)** what are the methods and tools **(interventions)** used to identify and measure self-identity **(outcome)?"***

2.9.2 Search strategy

A successful search strategy is one that is sensitive, specific, and systematic; sensitive, so important information is not missed and the search is complete, specific (need for efficiency), and systematic with a carefully defined strategy that can be repeated by others if necessary.

<u>Search inclusion and limits</u>:

Inclusion criteria applied to the search included data incorporating worldwide research due to the precise nature of the topic. Research focusing on measurement of self-identity in dementia in a peer reviewed journal and diagnosis or type of dementia confirmed, and data with direct relevance to the study research question and objectives. No methodological filter was initially applied to ensure sensitivity of the search to include all types of study design. Search limits were later applied to increase specificity, and included publication year (from year 2000 ensuring current research, but was increased to include research from 1990 which had a significant contribution to the search), language (English language due to resource limitations for translation) and publication type (for example journals, case reports, research papers, and secondary synthesis including literature reviews, narratives and editorial comments).

<u>Search resources:</u>

Searches for this literature review were made through the Cochrane Database of Systematic Reviews (CDSR) and search databases using EBSCO hosting, in order of search included PsychInfo, Medline and CINAHL.A description of the databases searched can be found in Table 2.

Table 2 Description of databases searched

Databases searched	Brief Description	Dates
The Cochrane Database of Systematic Reviews (CDSR)	The Cochrane Database of Systematic Reviews (CDSR) is the leading resource for systematic reviews in health care. The CDSR includes Cochrane Reviews (the systematic reviews) and protocols for Cochrane Reviews, as well as editorials. The CDSR is updated regularly as Cochrane Reviews are published.	N/a
PsychInfo	4 million records of behavioural and social science research, dissertations, and scholarly literature abstracts with a broad view of the field. With relevance to a host of related disciplines, including neuroscience, business, nursing, law, and education.	2000 - Present
Medline	The Medical Literature Analysis and Retrieval System, 21 million records from 5000 publications focusing on the life sciences and biomedical information.	2000 - Present
CINAHL – Cumulative Index to Nursing and Allied Health Literature	Resource for nursing and allied health professionals, students, educators and researchers. Focuses on United Kingdom and worldwide nursing and allied health subjects from more than 3000 journals dating back to 1981.	2000 - Present
Google / Google Scholar	Widely used internet search engine that uses text matching techniques to find web pages.	No date was set but the search ended when the citations no longer appeared relevant to the topic.

The Cochrane Database of Systematic Reviews (CDSR) is a resource of over 4000 systematic reviews in health care; it can guide selection of a topic as well as being a fundamental resource of relevant articles. This was the starting point for the search due to the sensitive, authoritative, relevant and reliable evidence it holds.

Searching then focused on the specialist PsychInfo database, which holds journals from the fields of psychology and behavioural and social sciences, moving onto Medline, a specialist database of journals focusing on health and life sciences, with the last database, CINAHL, a resource centred on nursing and allied health professions. Lastly, an examination of current literature using the internet search engine Google and Google Scholar was undertaken. A further resource used was research cited by the authors of identified studies.

The strategy included grey literature, information not produced by commercial publishers, which can include conference proceedings, theses or research reports.

Hand searching was used to select the most important journals for the review (for example Nursing Older People; International Journal of Geriatric Psychiatry), and was conducted using University of Portsmouth and NHS library resources and searching each one individually, by hand, with the specific criteria in mind. Sections/Chapters in books, conference papers, white papers and reports produced by government departments or academics were included.

<u>Search terms:</u>

Within the selected databases, free text search terms originated from the PICO framework and MeSH (Medical Subject Headings, used within specific search databases) or thesaurus synonyms and terms were identified and applied. Within

the selected databases, search terms were combined with Boolean Operators, including the "OR operator" to locate records matching any or all of the specified terms and "AND operator" to locate records containing all of the specified search terms. The positional operator ADJ was used to locate records in which a field contains all search terms adjacent to each other and in the order they were entered. Terms were truncated to include different word endings, and further functions such as double quotation marks allowed for specific terms or spellings of terms (for example self identity and self-identity) to ensure maximum sensitivity.

2.9.3 Literature review search results

From all the available sources, the original search provided 2337 articles, book chapters and related resources. Titles and abstracts were screened and 2168 were initially rejected as they did not meet the inclusion criteria. The remaining 169 items were reviewed, with content analysed and evaluated from the viewpoint of the study question; 89 articles were selected and duplicates from different systems were removed, with 57 articles identified that were relevant to the research study.

The search was replicated in 2016, which resulted in a total of 146 citations being identified. Thirty of these were duplicates, leaving 116 citations for review, where 88 were disregarded due to relevance of search criteria, resulting in 28 papers for review; 16 qualitative papers and 12 quantitative papers.

Assessment of the abstracts included preservation of self, social aspects of selfhood, the environmental impact on self and individual experience of care homes, and quality of life measures with identity included, qualitative descriptors of self-identity, narratives and case studies. Sixteen papers were qualitative studies

that aimed to describe self-identity dimensions or aspects of self-identity and the impact that dementia has on self-identity.

2.10 Summary and review of the qualitative studies of self-identity in dementia

Sixteen qualitative papers from the identified 116 published studies met the inclusion criteria for the literature search specific to self-identity in individuals with dementia and were relevant to the review. Full text versions of these papers were obtained and critically appraised, resulting in a tabulated summary detailing the author, date of publication, study aim, study design, setting, sample, and severity of dementia, main findings and summary of the critique of the study (Table 3).

The qualitative studies used a range of methods to explore self-identity in dementia, including thematic reviews (Caddell and Clare, 2010, 2011, 2012a and 2012b), narratives (Crichton and Koch, 2007 and Westius, Wallenberg and Norberg, 2010), recorded conversations (Tappen, Williams, Fishman and Touhy 1999), videotaped conversations (Mayhew, Acton, Yauk and Hopkins, 2001), observation (Small, Geldart, Gutman and Scott, 1998 and Ryvicker, 2009), case studies (Sabat, 2002), and unstructured or semi-structured qualitative interviews (Hedman, Hansebo, Ternestedt, Hellstrom, and Norberg, 2014).

Impelled to ask the question "*Can the self be lost?*", Sabat and Harre (1992) explored the application of social constructionist theory of the nature of the self, resulting in a three-part framework to describe self-identity; an intact self (Self-1) can be confirmed through a person's use of first person references to self, (I, me, myself, mine and my). Self-2 is "*comprised of a persons' physical and mental*

attributes and beliefs about those attributes" (Sabat, 2002, p.27) and Self-3 is the "personae" that demonstrates an individual's social and public self.

 Mayhew et al (2001) and Tappen et al. (1999) utilised the framework of Sabat and Harre (1992) and were able to establish evidence of the preservation of self with individuals with severe dementia. Despite the work of Tappen et al. (1999) being an older study which used proxy consent, they recruited a sample which included individuals across the spectrum of dementia stages. Analysis of tape-recorded conversations of everyday activities included frequent references to self, self-awareness and insights previously assumed "lost". Although these studies identified the preservation of self in dementia, much of their work was theoretical with limited clinical benefits indicated. Sabat (2002) later demonstrated how the social constructionist framework of the three types of self (Self-1, 2 and 3) could be practically applied to conversational-based therapy for people with milder cognitive deficits as a means to overcome the potential erosion of Self-3 Further work from Small et al. (1998) explored the role staff had in eroding the well-being and integrity of the individuals identity and the means to avoid these practices. Research conducted by Fazio and Mitchell (2009) strengthened the premise of the social constructionist view, by acknowledging that a failure to recognise the need to maintain self-identity in dementia results in significant detriment to the individual. The work of Sabat (2002), despite only having one in-depth case study, successfully explored how self-identity can be measured and implemented in therapeutic practice. Many of the qualitative studies emphasised the strength of the social constructionist approach throughout the progression of the illness, including Small et al. (1998), Tappen et al. (1999) and Fazio and Mitchell (2009).

Interviews were the most frequently used qualitative method of collecting data (Crichton and Koch, 2007, Surr, 2006 and Caddell and Clare, 2011). There was an over-reliance on the use of the Mini Mental State Examination (MMSE, Folstein et al., 1975) scores of participants to guide involvement in research. Eight studies included those with a MMSE of 18 or more which indicated a higher level of cognitive functioning and communication skills to elicit the thoughts and feelings of people with dementia on their self-identity in earlier stages of the illness. One study (Macrae, 2010) did not use any formal assessment of the severity of dementia for their participants, and two Swedish studies used alternatives to the MMSE, Westius et al, 2010 and Hedman et al., 2014 both of whom did not detail what the alternative was, yet there were clear clinical indications from their findings.

Thematic analysis of data collected on self-identity in dementia included Rosenthal's five stage interpretative biographical approach developed specifically for that study by the researcher, ethnographic approaches, participatory story-telling to provide a narrative, and two studies used interpretative phenomenological analysis (Caddell and Clare, 2011 and Pearce, Clare and Pistrang, 2010). Other studies did not describe any detail of their data analysis, providing "*coding and analysis procedures*" (Hayes, Boylsteinc and Zimmermanb, 2009) and "*qualitative data analysis as outlined by Coffey and Atkinson (1996)*", as stated by MacRae (2010, p.295).

Examples of these approaches include the work of Surr (2006), Crichton and Koch (2007) and Edvardsson, Featherstonehaugh and Nay (2010), indicating that qualitative methodologies were effective in eliciting person centred information

from those with dementia to identify and describe core elements of self-identity throughout the illness.

2.10.1 Limitations of qualitative studies

Only one qualitative study had a multi-informant approach (Edvardsson et al., 2010) where the individual with dementia, their informal carer and formal carer were included to gain a comprehensive view of self-identity. Most of the studies interviewed those with dementia in community settings, either in their own home, care homes or day care settings, or at the mild to moderate severity of the illness. None of the studies were conducted in an acute psychiatric in-patient care environment.

The management of self following diagnosis of dementia and greater understanding of the illness were identified as important, with social roles, family and relationships playing a supporting function for those with dementia, contributing to the continuity of self.

The importance of communication was highlighted throughout many of the qualitative studies, and its role in individuals expressing aspects of self was explored, with the most advanced individuals being able to express aspects of self-identity.

The qualitative approaches identified, described and explored aspects of self in those with dementia, including its preservation and methods of ensuring the continuity of self-identity as the illness progresses, contributing to a greater understanding self-identity, maintaining a sense of self, dignity, and relative well-being.

Table 3 summarises the author(s) of the qualitative research, year of study and country the research originated from. It details the study population and setting, the purpose of the study, its methods and qualitative analysis, and main findings.

Table 3 Summary of qualitative research; case studies, literature reviews and narratives on self-identity in dementia

	Author(s) / Year of study and country of research	Study population and setting	Purpose of study, aims and objectives	Methods and data analysis	Study findings
1	**Small, Geldart, Gutman and Scott** **(1998)** **CANADA**	17 residents living with dementia, aged 69-95 years, 25 nursing staff.	To measure of the integrity of self in dementia through verbal and non-verbal behaviours.	Videotaped observations of interactions between staff and residents collected over three days, data transcribed and analysed using discourse analysis.	Self does decline in dementia. Noted that half of residents used first person pronouns, but evidenced the maintenance of self in other methods such as defending their rights and cognitive resilience. Importance of care staff indicated in reinforcing aspects of self. Critique: Reflects work of Sabat and Harre's (1992) framework on Self types. Rationale for study unclear. Not based in hospital, residential home. Methodological aspects unclear ie how chose residents. Proxy consent gained. As older paper does not reflect cultural changes in dementia care. Role of staff detracting from well-being and eroding the integrity of self-identity.
2	**Tappen, Williams, Fishman and Touhy** **(1999)** **USA**	23 participants from nursing homes with Alzheimer's disease; 4 males, 19 females, MMSE range 2-18.	To obtain objective evidence of the persistence of self in advanced Alzheimer's disease and discover if evidence exists of an awareness of self.	Conversational analysis of 45 tape-recorded conversations.	First person used frequently and consistently supporting Social Construction Theory Self-1. Attitudinal aspects of carer affecting care and implications for nursing practice. Can be used as a measure of selfhood throughout duration of dementia. Critique: Older study –proxy consent obtained. Implications for clinical nursing practice. Minimal explanation of methodology. Referring to participants as 'MMSE 14' or 'MMSE 15'.
3	**Mayhew, Acton, Yauk and Hopkins** **(2001)** **Country of origin not stated**	5 participants with advanced Alzheimer's disease: 4 men and 1 woman MMSE range from 0-7.	To demonstrate the premise that there is an awareness of self in advanced dementia.	Exploratory qualitative study using videotape to critically analyse conversations between a nurse and individuals with dementia.	Those with advanced dementia demonstrated an awareness of their cognitive decline. Self and well-being were expressed, including a range of emotions, initiating social interaction and assert desire or will, show humour and pleasure and express creativity Critique: This supports the Social Constructionist Theory of preservation of self in dementia. Small sample, MMSE range very low. 0?

4	Sabat (2002) USA	One female participant, 75 years old, with Alzheimer's disease. MMSE 9.	To identify Social Construction Theory in an individual with Alzheimer's disease and explore the preservation of selfhood.	Case study / transcribed conversations.	Interpretative approach to support Social Construction Theory of three types of Self; Self 1 (self of personal identity), Self-2 (beliefs about attributes) and Self-3 (social personae). Can be used to identify aspects of selfhood throughout illness of dementia. Critique: Only a case study presentation – no further participant corroboration. Demonstrated aspects of theory and framework. Minimal discussion, conclusions or implications for further research. Practical application of theory.
5	Pearce, Clare and Pistrang (2002) UNITED KINGDOM	20 male participants with Alzheimer's disease, age range 63-84 years, MMSE 18 or above, living in the community.	Exploration of the appraisals and coping skills on men with early Alzheimer's disease and managing their sense of self.	Interviews and interpretative phenomenological analysis (IPA).	Clear themes identified on maintaining a sense of self with 7 sub-themes and reappraising and reconstructing a sense of self. Highlighted importance of understanding construction surrounding illness and the effect it has on managing self. Critique: Male dominance of participants, not able to generalise. MMSE 18+. Insights to self-identity specific to male gender but not identified in write up of research.
6	Surr (2006) UNITED KINGDOM	14 participants with dementia from 4 care homes, 13 female, 1 male, age range 72-94 years and MMSE scores 20 or less.	Exploration of self using a socio-biographical theory and its relevance to those in care homes.	Unstructured interviews and analysis using interpretive biographical methodology to examine relationships, social context and storytelling, and how these impact on the self.	Evidence found that supports the socio-biographical theory. Relationships, family, social roles caring for others and being cared for were important aspects of self in this group. Indicates that psychological and embodied factors are relevant to the self in those with dementia. Critique: Good background literature. Social situation and self no other philosophical aspects discussed. Based in residential care, why not a hospital base? Verbally articulate as a measure if able to articulate – very subjective. Female perspective bias – possible influence in results ie with family relationships with others and staff. Good examples from participants included. State that social aspects significant but only from female perspective. Future research areas identified.

7	**Crichton and Koch** (2007) **AUSTRALIA**	7 participants, one person with dementia, her family and members of health and social care.	Proposed that curation for and with the person with dementia can reproduce and reconfirm their identity.	Data collected over 6 months - interviews and stories woven into one narrative using a participatory story telling approach.	Curation to reconfirm identity has five methods: language, interaction, institutional care, in understanding and in research. Curation is necessary for the maintenance of self-identity living with dementia. Critique: Interdisciplinary approach to research – multi informant. Majority of results descriptive and specific to this case – generalisability? Looking at self-identity as narrative. Research and learning on-going. Importance of network around someone living with dementia.
8	**Fazio and Mitchell** (2008) **USA**	78 participants, age 66-103 years, mild and moderate Alzheimer's disease, 57 females, 21 males.	Persistence of self-identity evidenced through language used and self-recognition in those with Alzheimer's disease.	Analysis of discourse for evidence of self-references throughout test/retest, as well as recognition of self through photographs.	Identified the need to change attitudes towards self in those with Alzheimer's disease. Research supports the persistence and consistency of self and the findings of Social Construction Theory. Critique: Large sample, importance of language in dementia care- MMSE range not provided – not hospital based. Detailed methodology. No discussion of ethics. Detailed focus on types of communication identified - identity not lost altered.
9	**Ryvicker** (2009) **USA**	Residents in 2 care facilities which represented contrasting models of care: home versus hospital.	Identification and measurement of staff practices that preserve or hinder the concept of self.	Ethnographic data from field notes taken over one year. Grounded theory analysis of data.	Staff interventions and engagement both support and interfere with preservation of self. Barriers to providing person centred care in a medical model and in a family atmosphere. Both models have contradictory effects on the resident's preservation of self. Identification of the challenges of care provision and implementing care. Critique: Original research - observation/ethnography minimal discussion of methods used. Can see implications for nursing practice developments. Role culture has in implementing change for the benefit of older adults in care environments.

10	Westius, KallenbergandNorberg (2010) SWEDEN	21 participants with mild to moderate Alzheimer's disease, 12 women and 9 men aged 61-89 years.	Do people with mild or moderate Alzheimer's disease regard their personal life as a vital aspect of their sense of identity?	Narrative interviews tape recorded and transcribed verbatim. Phenomenological hermeneutic method used to form explanations from the data collected.	Three themes identified; view of life as vital aspect of sense of identity, valuing life in terms of meaning and connecting to ones sense of identity, and expressing continuity on central values, emotional attitudes and identity. Critique: Effective and detailed measurement of self-identity. Links to theoretical stance and pulls on research listed here. Pilot before study. Used alternative to MMSE. Full discussion and disclosure of ethical considerations.
11	MacRae (2010) CANADA	9 participants diagnosed with early Alzheimer's disease, 7 men, 2 women, age range 60-85 years.	Investigation of the effect of Alzheimer's disease on identity.	Interviews were conducted, transcribed and the data analysed for themes.	Four themes emerged: Who am I?, perceived changes in self, concerns about loss of self and maintaining identity. With the correct resources those with Alzheimer's disease can live well with the illness and in contrast to previous research the participants did not disclose a high level of concern about loss of self through dementia. Critique: Threats to identity identified. Aims of research not clear. Small sample mostly men (unusual!)No formal assessment of severity of dementia. Role of resilience and resourcefulness, Corroborated other research on identity continuity. Social role in maintaining identity.
12	Edvardsson, Featherstonehaugh and Nay (2010) SWEDEN	11 participants with dementia, 37 care staff and 19 family members.	Identification and description of a continuity of self through person centred care	Transcribed interview texts analysed using qualitative content analysis.	The core aspects of person centred care were promoting a continuity of self and normality, 5 other content categories contributed including: knowing the person, welcoming family, providing meaningful activity, being in a personalised environment, and experiencing flexibility and continuity. Critique: Convenience sample – bias? Multi-informant design. Data analysis not able to succinctly fit into content analysis affecting credibility of results. Minimal clinical implications of the work outlined.

13	Nowell, Thornton and Simpson (2011) UNITED KINGDOM	Seven participants, 3 females, 4 males, age range 62-87.	To understand the subjective experience of dementia in United Kingdom care settings.	Semi-structured interviews and interpretative phenomenological analysis (IPA)	Three key themes emerged; adaptation to the illness, using past roles to manage the experience of the present, and conflict of social and individual roles and functioning. Effective in measuring aspects of self-identity. Critique: Small sample used IPA within other research studies. Emphasis on social interaction. Only used individuals with early onset dementia. Considered capacity to consent. Ethical approval obtained. Adaptations to interview schedule for those with cognitive impairments. Up to date literature review. Unable to distinguish between self and personhood throughout. Demonstrated how social groups affected care of those with dementia. Skill in adapting to social situations maintained in early dementia.
14	Caddell and Clare (2012a) UNITED KINGDOM	N/a	To identify interventions that support self and identity in people with dementia, and discuss the features of those interventions, the outcomes measures and conclusions derived from the research.	Systematic review, 39,543 papers identified, 10 studies met the inclusion criteria: 3 distinct groups of studies, - those not described as a specific aim, studies that specifically stated that the aim was to support self and lastly those with outcome measures.	All studies described some benefit of interventions for people with dementia, but details varied and positive results based on the therapy were provided. Some studies had no formal outcomes measures. Large variation in theoretical background used, study design, sample, and intervention and outcomes. Discussion of strengths and limitations of studies, also highlighting that further investigations needed. Critique: Identified problems in drawing conclusions in previous research. Uses multi-design approach including TSSC, SIDQ, AMI, HADS and QoL-AD. Procedures unclear informants and participants 'helped' by researcher? Did revisit on several occasions if needed. Statistical analysis overly complicated to identify conclusions. Participants had MMSE +18 and volunteered possible bias and sample size small.

15	Caddell and Clare (2012b) UNITED KINGDOM	10 participants, with dementia, MMSE scores of 18 and above, 5 men and women age range between 65-88 years.	Focus on the individual's subjective experiences and whether they felt they had changed as a person and what sort of person they were. Impact of dementia on identity.	Semi-structured interviews with open-ended questions and interpretative phenomenological analysis (IPA).	Four themes emerged, but for each there were aspects of continuity or change identified: "I am still the same person" versus "I'm different to what I used to be", "I'll always stay the same" versus "I'm not sure what to expect", "Life is much the same" versus "It is affecting my life", "Always that connection" versus "It's not just me". Critique: Identified problems in drawing conclusions in previous research. Uses multi-design approach including TSSC, SIDQ, AMI, HADS and QoL-AD. Procedures unclear informants and participants 'helped' by researcher? Did revisit on several occasions if needed. Statistical analysis overly complicated to identify conclusions. Participants had MMSE +18 and volunteered possible bias and sample size small.
16	Hedman, Hansebo, Ternestedt, Hellstrom and Norberg (2014) SWEDEN	10 participants with mild to moderate Alzheimer's disease, 5 males, 5 females, age range 65-80 years.	To use Harre's theory of selfhood to describe how people with mild to moderate Alzheimer's disease express their sense of self.	Semi-structured interviews, audio-recorded, transcribed verbatim and content analysed qualitatively using Harre's theory to identify participant's expressions of sense of self.	Evidence was found with expressions of Self-1, Self-2 and Self-3.Changes were identified in each aspect of self, highlighting that there was positivity with regard to coping skills and adapting to the illness, with people perceiving themselves as the same person as before they were diagnosed. Critique: Used Sabat and Harre's(1992) framework. Participants all volunteered. Alternative to MMSE used. Young cohort of participants. Builds upon Sabat's early work (2002). Minimal transferability to other contexts. Clinical implications outlined.

2.11 Quantitative measurement of self-identity in dementia

Twelve quantitative papers from the 116 published studies met the inclusion criteria for the literature search specific to measurement of self-identity in individuals with dementia and were relevant to the review. Full text versions of these papers were obtained and critically appraised, resulting in a tabulated summary detailing the author, date of publication, study aim, study design, setting, sample, and severity of dementia, main findings and critique of the study (Table 4). However, the lack of agreed definition made it difficult to appraise and compare research undertaken, with "disparate evidence" on the concept of self-identity (Caddell and Clare, 2010, p.114).

In an early but influential review of measurement of self-identity, Burke and Tully (1977) claimed that there are four criteria that need to be met when measuring identity. It: (i) must produce a quantitative measure, (ii) must produce a measure that incorporates the multi-dimensional character of role and identities, (iii) must adequately define the points that give meaning to the quantitative scores, and (iv) should integrate the concepts of self and role.

Quantitative approaches used to investigate the concept of self-identity in dementia included questionnaires (Cohen-Mansfield et al., 2000, Caddell and Clare, 2012a, 2012b), self-assessment tools (Cottrell and Hooker, 2005), and Likert-scales to rate a specific aspect of self-identity (Tennessee Self-Concept Scale [TSCS] and the Self-Knowledge of Personality Traits) as used by Naylor and Clare (2008) and Caddell and Clare (2012a, 2012b).

Three research studies used multiple measurements to study identity (including the Self-Identity in Dementia Questionnaire [SIDQ] and TSCS), such as Caddell and Clare (2012a, 2012b) and Eustache et al. (2013).

The TSCS consists of 100 self-descriptive items exploring how an individual portrays who he or she is, their personal preferences, and their feelings. The scale summarises an individual's feelings of self-worth and the reality of self-image. In addition, the tool measures five external aspects of self-concept (moral-ethical, social, personal, physical and family) and three internal aspects (identity, behaviour and self-satisfaction). Both studies were able to elicit components of identity that were preserved, but the tool is primarily for measurement of self-concept, with only a small element specific to self-identity. Lastly, the TSCS does not have a multi-informant design, and Clare et al. (2013) used the tool but involved carer proxy ratings on self-identity and not the individual's own rating.

Eustache et al. (2013) was the only identified research study from the review that measured sense of identity in individuals with dementia changing over a period of time. The research used a two-week period, but this was identified as a limitation of the study due to insufficient time to establish the stability of an individual's self-identity. They concluded that sense of identity was preserved in individuals with Alzheimer's disease, with a consistency of scores over the two-week period studied, and similarities were identified between those with Alzheimer's disease and healthy participants.

The Quality of Life-Alzheimer's disease is a 13-item self-report scale that assesses physical health, mental health, social situations and financial domains of functioning in people with Alzheimer's disease. Each item asks about a specific

aspect of one of these domains and the respondent is asked to rate how he/she feels about this aspect of his/her own life on a four-point scale, from "poor" to "excellent". Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4.The score is the sum of all 13 items, out of a total of 52. The tool can be used as a single assessment of quality of life, or it can be used as a comparison between and informant and the individual with dementia.

Elements related to self-identity include a focus on the quality of family roles and relationships and relationships with friends and questions related to self, eg "How do you feel about yourself? When you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?"

Whether this tool is specific enough to aspects of self-identity has been debated and it was not included in Caddell and Clare's (2010) systematic review of the impact of dementia on self and identity. However, this measure was used in several subsequent research studies related to self-identity in dementia including Jetten et al. (2010) and Caddell and Clare (2012a and 2012b).

Jetten et al. (2010) investigated the relationship between cognitive impairment and identity loss in those living with dementia. Due to the research team adopting an autobiographical memory approach to self identity, they concluded that those "suffering" from dementia and memory loss, their overall well-being was compromised, as measured by the QoL-AD.

Further aspects of identity and well-being related to changes in self-identity were explored by Caddell and Clare (2012a and 2012b). Their cross sectional study aimed to determine the relationship between identity, mood and quality of life (QoL) in individual in the early stages of dementia. Using this tool with additional

measures (the Tennessee Self Concept Scale and Self-identity in Dementia Questionnaire), they were able to determine aspects of identity that could predict a relationship between anxiety, depression, and quality of life. It was only through the use of the QoL-AD and these additional measures that they were able to conclude that supporting identity in people with dementia who are experiencing difficulties in this regard might have a positive impact on mood.

However, as this the QoL-AD focuses on physical health, mental health, social situations and financial domains of functioning in people with Alzheimer's disease, it does not specifically measure self identity. In the preliminary stages of this research study whereby potential tools were critically reviewed to measure identity, the QoL-AD was deemed inappropriate and therefore not chosen for use.

Cohen-Mansfield et al. (2000) used a three stage exploratory study to develop a systematic method for the assessment of self-identity in dementia. This study met the guidelines as proposed by Burke and Tully (1977). The Self-Identity in Dementia Questionnaire (SIDQ) aimed to explore four domains of self-identity: occupation, family membership, leisure activities and personal attributes from a multi-informant perspective (individual with dementia, the informal carer and staff member). A multi-informant approach was justified by Cohen-Mansfield et al. (2000), who stated that due to language and communication deficits experienced with dementia, an individual's sense of identity could be examined by those within their familial, social and health environments to determine strength of understanding of the concept of self-identity. Additional questions for the family and formal carer were included, specifically focusing on the preservation of self-identity of the individual with dementia. Only one other study within the literature

review used a multi-informant approach of three participant groups (Edvardsson et al., 2010).

Using a new methodological approach, Cohen-Mansfield et al. (2000) investigated previously unexplored empirical issues of self-identity in dementia such as attempting to understand the sense of identity of those with dementia from a multi-informant perspective, as it had often been a *"neglected"* subject (Cohen-Mansfield et al., 2000, p. 382).

Due to its exploratory qualities, the research study triggered questions which were a springboard for the research team to continue investigation in this area. The new focus was on the differences between the SIDQ multi-informants (Cohen-Mansfield et al., 2006b), how the SIDQ could inform care staff of role appropriate interventions and activities to engage people with dementia (Cohen- Mansfield et al., 2006b), and the impact of stimulus attributes on nursing home individuals with dementia (Cohen-Mansfield, et al., 2009b). Cohen-Mansfield et al. 2010a demonstrated how the SIDQ data had clinical implications, influencing engagement levels of those with dementia, and demonstrated that the meanings behind stimuli can effectively engage the individual if based upon their identity (Cohen-Mansfield, et al., 2010c).Cohen-Mansfield et al. (2000, p.392) recognised there were potential cultural barriers of the tool, stating that the questionnaire could be modified to fit different cultures.

Table 4 summarises the quantitative research included in the literature review. It details the study author(s), date and country of origin. It also documents the study aim and design, including study setting, sample size and severity of dementia. The

measures used within each of the studies are highlighted within the table, with the main findings and critique of the research outcomes provided.

Table 4 Summary of quantitative research using measures of self-identity in dementia

	Author (date) and country of origin	Study aim	Study design (including study setting, sample size, age and severity of dementia)	Main findings	Critique: Strengths and weaknesses of study
1	**Jensen, Huber, Cundick and Carlson.** **(1991)** **USA**	Examination of a model of self-development and a scale to measure 12 aspects of self.	Obtained a list of self-constructs and condensed into 192 self-descriptive items in 15 categories. Further reductions to 166 items. **Two new scales resulted; *Self-security and Self-cognizant measures.***	Development of a new measure for self-identity.	In-depth analysis of measures of face validity, with testing and re-testing as measure developed. Reliability assured and a considered as a useful research tool. No mention of clinical implications of tool. Acted as a catalyst for further studies using tool.
2	**Cohen-Mansfield et al.** **(2000)** **ISRAEL**	To explore role identity in those with dementia and assess potential of using data to enhance quality of life.	Two Israeli nursing homes, 38 residents, age 56-89, MMSE 0-22, multi-informant design (individual with dementia, relative and staff member). **Measure used; *Self-Identity in Dementia Questionnaire.***	Development of new measure for self-identity. Family role identified as most important to those with dementia, with a range of roles identified using the measure, showing attributes and traits that are important and which will contribute to preservation of self. Ways to elicit identity were identified, including influences on resident, activities to enhance identity, and how important an individual's name is. Levels of agreements between informants and consistency and change throughout dementia also demonstrated.	Comprehensive assessment of aspects of identity in dementia. Identified that tool could be used within a different culture, generic questions which can be modified. Clinical implications including how completing the questionnaire can be used to build therapeutic relationship with individuals and their carers.

	Author (date) and country of origin	Study aim	Study design (including study setting, sample size, age and severity of dementia)	Main Findings	Critique: Strengths and weaknesses of study
3	**Cotrell and Hooker** **(2005)** **USA**	To assess the usefulness of possible selves as a framework for investigating the perspectives of people with dementia.	Comparison between community based individuals with AD (n=50, MMSE 10-29) and cognitively intact (n=50, MMSE 28+). **Measures used;** ***Possible Selves Interview measure, Philadelphia Geriatric Centre Positive and Negative Affect Scale, Deficit Awareness.***	High levels of similarities between individuals with AD and those cognitively intact; hoped for selves mentioned family and health and most feared were health and bereavement. Multivariate analysis and comparisons between AD group and cognitively intact group – looking at dementia related selves, factors related to independence and personal aspects, abilities, memory and affect, family relationships and awareness of deficits.	Original study, all results were exploratory – tools used were able to determine stability of self, identifying resources used by individuals with both AD and cognitively intact to manage in later life. Small sample so poor generalisability. Self-report for those with AD identified under reporting of depressed mood and lack of differentiation between clinical depression and emotional experiences. Unable to determine change of dementia related selves over time and as illness progresses.
4	**Naylor and Clare** **(2008)** **UNITED KINGDOM**	Exploration of the relationship between autobiographical memory, identity and awareness in early dementia.	Correlational design, recruited from a memory clinic, n=36, mixed diagnoses, MMSE 18+ **Measures used;** ***Clinical Dementia Rating Scale, Autobiographical Memory Interview, Tennessee Self-Concept Scale, Memory Awareness Scale, Rivermead Behavioural Memory Test.***	Relationships between autobiographical memory, identity and awareness examined – specific tests calculated for different diagnoses of dementia. Greater recall from earlier life periods, those with higher MMSE scores more successful in recalling recent semantic information. No straight forward connection between impairment in autobiographical memory and self-report of identity and lower awareness of memory issues demonstrated a more positive and more definite sense of self – hypothesis of higher levels of awareness of memory functioning and stronger sense of identity was not supported.	Favourable ethical opinion sought and agreed. Used well validated measures. Similar to results from earlier studies (Addis and Tippett, 2004) Small sample size affecting statistical analysis. Identified that participant's found the Tennessee Self-Concept Scale challenging. Identified areas for further research.

	Author (date) and country of origin	Study aim	Study design (including study setting, sample size, age and severity of dementia)	Main Findings	Critique: Strengths and weaknesses of study
5	**Jetten, Haslam, Pugliese, Tonks, and Haslam.** **(2010)** **UNITED KINGDOM**	Investigation of the impact of cognitive impairment and identity loss of older adults with dementia	Three groups of older adult participants; 17 independent in community, 15 care home residents and 16 in specialist dementia units. **Measures used;** *Autobiographical memory Interview, a questionnaire for personal and social identity measures, Quality of Life-AD, Addenbrooke's Cognitive Examination-Revised.*	Fair and good levels of life satisfaction, lowest for the care home group, no difference between community and specialist dementia group. Autobiographical retrieval was highest in the community group, large differences in ACE-R results as expected. Large differences between the groups in personal identity strength, lowest for care home and specialist dementia group. Linear decrease in ability on objective and subjective measures of cognitive function. Community scored better than care home and they scored better than those in the specialist dementia units. Well-being was not negatively affected by increasing levels of care and memory loss in a linear fashion.	Adherence to the Mental Capacity Act to recruit those who are deemed to lack capacity. Participants able to understand questions posed and no data missing as required for analysis. No details of the type of "questionnaire" used to measure personal and special identity. Analysis of results clear and well presented in the article. Assumptions made in introduction with no evidence base. Cites Cohen-Mansfield study (2000). Predominantly female participants. Dementia type not looked into. AMI and QoL-AD used. Overcomplicated results section. Small sample size. Dementia 'sufferers' poor use of language considering less than 10 years old. Further study required.
6	**Haslam, Jetten, Haslam, Pugliese and Tonks.** **(2011)** **UNITED KINGDOM**	Exploration of relationship between episodic and semantic self-knowledge and identity strength.	32 participants in tot, 17 from community environments and 15 in residential care. **Measures used;** *Autobiographical Memory Interview, and Addenbrooke's Cognitive Examination-Revised*	No differences noted between community and residential groups. Those in care retrieved fewer personal semantic and episodic memories. Those in the community setting had stronger personal identity strength but not in social identity. Both autobiographical memory components were associated with integrity of self.	Evidence of co-design, involvement of Age Concern to assist with study. Lists of questionnaires related to personal and social identity but no specific tool described. In-depth analysis of proposed tool. No causality determined, but data was correlational and cross-sectional.

	Author (date) and country of origin	Study aim	Study design (including study setting, sample size, age and severity of dementia)	Main Findings	Critique: Strengths and weaknesses of study
7	**Fargeau et al.** (2010) **FRANCE**	To explore changes in self in patients with Alzheimer's disease.	N=47, Group 1 MMSE >20, Group 2 <20 - Diagnosed with dementia. **Measures used;** *Clinical Dementia Rating, Wisconsin Card Sorting Test, Apathy Evaluation Scale, Depression Scale, Self-assessment based on concept of self by William James; Material Self, Social Self and Spiritual Self.*	43/47 patients presented as an impairment in one dimension of the Self. When one self was affected it was always the Social Self. Two dimensions of self were impaired in 44.7% patients. All dimensions were impaired in 10 patients. Relationships determined between duration of illness, age, and educational status. Cognitive variables, WCST and behavioural variables, Significant correlation between severity of impairment of the Self and executive function (WCST) and apathy. Dementia impairs the Self-experience with the Social Self being most vulnerable.	Unclear separation in article regarding MMSE scores for groups – no further reference to groups, only disease duration. Unvalidated assessment tool for self and not acknowledged in text. Interesting discussions about Self and mood-related changes in dementia. Small sample size.
8	**Addis and Tippett** (2004) **NEW ZEALAND**	Identification of relationship between autobiographical memory and identity.	AD Group (n=20, MMSE 13-24) from home or residential homes and Control Group (n=20) living independently in the community. **Measures used;** *Autobiographical Memory Interview, Autobiographical Fluency Task, Tennessee Self-Concept Scale and Twenty Statements Test.*	Analysis between memory and impairment, those with AD performed poorly in the AMI compared to the control group. Recall was better in recent adulthood rather than early adulthood in those with AD, fluency of events and for names demonstrated poor performance in those with AD. Less response from the AD Group on strength of identity was identified, vague answers given but complexity of identity was no different between the two groups. Demonstrated a gradient loss of memory as dementia progressed.	Detailed descriptions of measures used and research that has used them previously. Indicated for first time changes in strength, quality and direction of identity in those with Alzheimer's disease compared to healthy older adult. Identified how two constructs of memory and do not map directly with each other.

	Author (date) and country of origin	Study aim	Study design (including study setting, sample size, age and severity of dementia)	Main Findings	Critique: Strengths and weaknesses of study
9	**Caddell and Clare (2012a)** **UNITED KINGDOM**	To determine if individuals with early stage dementia experience their sense of identity differently to healthy people.	Memory clinic patients. Cross-sectional questionnaires (n=50) with AD, vascular dementia of mixed dementia, aged 60+ and MMSE 18-29. **Measures used – *Tennessee Self-Concept Scale, Self-Identity in Dementia Questionnaire, Autobiographical Memory Interview, Hospital Anxiety and Depression Scale, Quality of Life-AD.***	Family role was most important for both groups, and occupational role the weakest. No participant met criteria for identity disorder. The healthy group scored significantly higher than the dementia group on measures of identity related distress (long-term goals, friendships, religion, values and beliefs) – supports the preservation of identity in those with dementia. Scores were similar across the groups for depression and self-esteem. Aspects of identity need to be considered in isolation rather than associated with each other – more a construct of multiple components.	Ethical approval included. Participants had varying levels of support when completing the measures, which may have induced bias into results. Need for future work identified focusing on changes in identity. Looking at many aspects of self-identity in dementia not just one aspect. Healthy people change identity in older age so why not those living with dementia? Multi method approach. MMSE range 18-29.Lots of statistical analysis but not much discussed. Only early stages of dementia. Results cannot be generalised.
10	**Caddell and Clare (2012b)** **UNITED KINGDOM**	To determine the relationship of identity with mood and quality of life in people with early stages of dementia.	Memory clinic patients. Cross-sectional questionnaires (n=50) with AD, vascular dementia of mixed dementia, aged 60+ and MMSE 18-29. **Measures used; *Tennessee Self-Concept Scale, Self-Identity in Dementia Questionnaire, Autobiographical Memory Interview, Hospital Anxiety and depression Scale, Quality of Life-AD.***	The role identity with highest score was family role and occupational role lowest. Demonstrated acute awareness of traits. Identified those with anxiety and depression in the cohort.	Original study using validated identity tools. Took individual abilities into account. Effectively identified relationships between mood and quality of life. Those who volunteered to take part represented a select group of individuals. Small sample size. Incomplete data sets for analysis. Did not state those identified with depressive /anxiety symptoms were signposted for support/treatment. Results cannot be generalised to individuals in more advanced stages of illness.

	Author (date) and country of origin	Study aim	Study design (including study setting, sample size, age and severity of dementia)	Main Findings	Critique: Strengths and weaknesses of study
11	**Martinelli, Anssens,Sperduti and Piolino.** **(2013)** **USA**	Investigation of the effect of normal aging and AD on the retrieval of self-defining memories compared with the retrieval of autobiographical episodes and personal semantics and the link between autobiographical memories, impairment and self-concept.	Two groups of healthy subjects, n=18 young adults and n=16 older adults with no memory complaints, and one group of n=10 with AD (MMSE 18+). **Measures used –** *Autobiographical episodes task, personal semantics tasks and self-defining memory tasks, Tennessee Self-Concept Scale.*	Compared with young adults, older adults and AD patients demonstrated a deficit in autobiographical episodes; nevertheless, the three groups performed equally for personal semantics. Older adults did not differ from young adults for self-defining memories characterized by high episodicity, unlike the AD patients.	Detailed descriptions of measures used. Statistical findings presented in such a way that made it a challenge to interpret them in a meaningful way and minimal explanation provided associated with the results. Identified areas for further research.
12	**Eustache et al.** **(2013)** **FRANCE**	To explore whether sense of identity persists in patients with AD and if its profile changes over time.	N=16 with AD and n=16 healthy elderly controls within a care home, MMSE 5-23. **Measures used –** *I-AM Test, IMAGE Test, Signoret's cognitive battery.*	I-AM Test showed differences between self-descriptions in two groups, the IMAGE test showed no significant difference between scores of the groups. For the AD group there were no differences in reliability between the two assessment time frames.	Adapted tools/tasks to ensure suitable for patient cohort, but may have had adverse impact on reliability and validity of tool (IMAGE). Qualitative and quantitative analysis to gain comprehensive picture of identity. Examined sense of identity changing over a period of time, but time period of two weeks too close to assess for any difference, but identified reliability in sense of self. Range of MMSE 5-23. I-AM test adapted twenty statements test – reliability of respondent's answers on two different occasions measured. Only a two week break – not considered enough time between tests. Female dominant sample. Complex methodology limited participant inclusion. Modified measures throughout the study – reliability?

2.12 Measures and tools of self-identity in dementia

From the research papers appraised, four measures were identified that had been specifically used to measure self-identity in dementia; Twenty Statements Test, Tennessee Self-Concept Scale (TSCS), Quality of Life-Alzheimer's Disease, (QoL-AD) and the Self-Identity in Dementia Questionnaire (SIDQ).

A tabulated summary of the measures identified throughout the literature was developed, detailing a description of the tool, the scoring system, reliability and validity, and research or clinical relevance (Table 5).

Table 5 Summary of quantitative measures of self-identity in dementia

Self-identity measure	Tool / Measure description	Tool / Measure scoring	Reliability and validity of the tool / measurement	Research and clinical indications
Twenty Statements Test **(TST)** **Kuhn and McPartland (1954)** The TST was developed as a way of determining the degree to which we base our self-concepts on our membership in different groups.	The test takes the form of a survey, with respondents asked to give up to twenty responses to the prompts, "Who am I?" or "I am..."- it is not mandatory that respondents give twenty answers. The test takes a few minutes. The test is unusual in utilising an open-question methodology; Kuhn (1954) has stated that responses to the TST should be grouped into five categories: social groups and classifications, ideological beliefs, interests, ambitions and self-evaluations.	There are two major schemes for coding the responses to the TST. The first is the compilation of the subject's locus score, which has been taken as a measure of the extent to which the subject is anchored in the social system. The second is the categorisation of the responses into the set of five analytical categories developed by Kuhn.	Significant inter-coder variation appears to exist, both between research coders themselves, and between them and the subjects as coders.	Advantages - A very quick and easy tool to implement as well as being easily accessible. Has been used in up to date research by Addis and Tippett (2004). Disadvantages - Methodological issues due to a complicated coding system, lack of consistency in coding, and newer self-identity tools are available.
Tennessee Self-Concept Scale **(TSCS)** **Fitts and Warren (1996)** Designed to summarise an individual's self-worth.	The Tennessee Self-Concept Scale (TSCS) consists of 100 self-descriptive items by means of which an individual portrays what he or she is, does, likes and feels. The scale is intended to summarise an individual's feeling of self-worth, the degree to which the self-image is realistic, and whether or not that self-image is a deviant one. In addition to an assessment of self-esteem, the TSCS measures five external aspects of self-concept (moral-ethical, social, personal, physical and family) and three internal aspects (identity, behaviour and self-satisfaction). In addition, crossing the internal and external dimensions results in the mapping of 15 "facets" of self-concept. It is administered in just 10 to 20 minutes.	The TSCS allows two scoring systems. The counselling form yields 14 profiled scores: self-criticism, 9 self-esteem scores (identity, self-satisfaction, behaviour, physical self, moral-ethical self, personal self, family self, social self, and total), 3 variability of response scores (variation across the first 3 self-esteem scores, variation across the last 5 self-esteem scores, and total), and a distribution score. The clinical and research form yields 29 profiled scores: the 14 scores in the counselling form and the following 15: response bias, net conflict, total conflict, 6 empirical scales (defensive positive, general maladjustment, psychosis, personality disorder, neurosis, and personality integration), deviant signs, and 5 scores consisting of counts of each type of response made.	Reliability: The reliability estimates for all TSCS scales are retest coefficients based on a sample of 60 college students over a two-week period and in general range from 0.60 to 0.90. Validity: The manual presents correlations between the TSCS scales and those of the MMPI, the Edwards Personal Preference Schedule, and several other well-known measures. A great many of these correlations are significant; so many in fact where the MMPI is concerned it appears the two inventories must be nearly completely overlapping. Researchers have reviewed a number of factor-analytic studies and concluded that none support Fitts' specific hypothesis of 15 dimensions of self-concept.	Advantages – Can be used in clinical practice as well as research, broad applicability and good reliability and validity. Updated version available. Disadvantages – Complicated manual and access issues, not available in the United Kingdom and expensive to purchase with all required resources. Recommended uses for the TSCS include the assessment of self-concept in clinical, counselling, and research settings.

Self-identity measure	Tool / Measure description	Tool / Measure scoring	Reliability and validity of the tool / measurement	Research and clinical indications
Quality of Life – Alzheimer's disease (**QoL-AD**) (**Logsdon, Gibbons and McCurry and Teri, 1999**) The QoL-AD is based on a literature review of QoL in older people.	This is a 13-item self-report scale that assesses physical health, mental health, social situations and financial domains of functioning in people with Alzheimer's disease. Each item asks about a specific aspect of one of these domains and the respondent is asked to rate how he/she feels about this aspect of his/her own life on a four-point scale, from "poor" to "excellent".	Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4. The total score is the sum of all 13 items with a possible total range from 13 to 52.	Logsdon et al. (1999) claim QoL-AD has good internal consistency, construct validity, and test-retest reliability. The QoL-AD was found to have very good inter-rater reliability across all 13 items and overall was found to have excellent internal consistency, indicating that the items can be summated as a scale.	Advantages - Brief, self-report scale, designed so that people with dementia and their caregivers may both complete. Disadvantages - The QoL-AD was designed for self-completion, but it was more often the case that the scale has to be completed in conjunction with the interviewer, particularly with people with moderate to severe dementia.
Self-identity measure	**Tool / Measure description**	**Tool / Measure scoring**	**Reliability and validity of the tool / measurement**	**Research and clinical indications**
The Self-Identity in Dementia Questionnaire (**SIDQ**) **Cohen-Mansfield et al. (2000)** Multi-informant Likert style questionnaire enquiring on four aspects of self-identity.	The Self-Identity in Dementia Questionnaire (SIDQ) aims to explore four domains of self-identity: occupation, family membership, leisure activities and personal attributes from a multi-informant perspective (individual with dementia, the informal carer and staff member). Close-ended questionnaires were developed for use with the resident, staff caregiver and relative.	Respondents are asked to rate the importance of each domain/role in the past and in the present on a seven-point scale, ranging from completely unimportant to very important. Additional questions related to self-identity are included for relatives and care staff.	Internal consistency reliability (scale reliability) of each of the four role identity subscales for family and staff informants on the basis of the four items of importance, attitudes, talks about role, and demonstration of the role in behaviour. For family informants, Cronbach's alpha for professional, familial, hobbies, leisure time, and achievements role identity scales were 0.82, 0.83, 0.82, and 0.84, respectively; for staff informants, the corresponding values were 0.85, 0.67, 0.84, and 0.87. Performed test–retest reliability of the questionnaire for a subset of family members (n-10), and it averaged an exact agreement of 86.2%. (Cohen-Mansfield et al, 2006)	Extensively used research and clinical tool – catalyst for further research studies by Cohen-Mansfield. Advantages - multi-informant design which can be implemented at any stage of dementia and concentrates on both behavioural and verbal aspects of self. Free access through the researcher. Used in additional studies by other researchers. Disadvantage – Time/resource intensive

2.13 Summary of self-identity in dementia and its measurement

A notable element from the literature review was the lack of published research on self-identity in dementia from the nursing profession. There has been an emphasis on delivering better research, a fundamental aspect of the Government's Challenge on Dementia, with a boost in research to generate the evidence needed to make changes in prevention, treatment and care. However, less than a quarter of authors of the studies included in this literature review identified themselves as holding a professional nursing qualification. Despite a quarter of the papers included in the study being affiliated with a nursing or health sciences department within a university, those papers often made minimal references to nursing clinical practice with the results from the research. Of those studies (both qualitative and quantitative) that did identify whether the researcher held a professional nursing qualification (Tappen et al., 1999, Mayhew et al., 2001, Cohen-Mansfield et al., 2000 and Edvardsson et al., 2010), the clinical implications for nursing practice were very clear, clearly communicating the benefits to patient outcomes, which may have been a consequence of having those within the nursing profession as a visible and influential aspect of the research published.

In summary, many of the earlier studies were a catalyst for further research, but there has been no newly published data within the past three years on the measurement of self-identity in dementia. Research on self-identity in dementia and its measurement has been based predominantly in the United States, with some conducted in European countries such as France, and additional work based in New Zealand and Israel.

Only five studies were conducted in the United Kingdom. This could possibly indicate differences in the research due to variances in healthcare delivery including cultural and societal differences. The studies reviewed were based in memory clinics, community settings, and nursing or residential care homes and not within a NHS secondary care setting such as an acute psychiatric in-patient ward. The reasons for the lack of research into this subject within an NHS in-patient setting are unknown.

Finally, there has been little research conducted at an acute stage of the disease reflecting a moderate to severe stage of the illness when acute psychiatric assessment is required of the patient's mental health needs associated with their dementia. The literature reviewed demonstrates that those included in the self-identity research predominantly had MMSE scores of 18 or over (similar to the qualitative studies), with only three quantitative studies including those with more severe cognitive impairments (Cohen-Mansfield et al., 2000, Addis and Tippett, 2004 and Eustache et al., 2013). It was not clear from those studies reviewed whether those diagnosed with dementia were in a "stable" phase of the illness or a more acute stage where the emergence of behavioural or psychological symptoms had emerged, which was identified as a limitation of these studies.

There is a gap in the research of how pertinent information regarding an individual's self-identity at the acute, more advanced stage of the illness could have a significant impact on their care, treatment and well-being. Research studies from the past 10-12 years based within acute old age psychiatry in-patient wards have focussed on; the effect of the acute general hospital setting on those living

with dementia (Bridges et al., 2010), the effectiveness of acute psychiatric treatment (Draper and Low, 2005), discharge processes and destination of discharge related to patient outcomes for those living with BPSD (Bucher et al., 2016 and Tucker et al., 2017), or staff perceptions of seclusion and restraint (Muir-Cochrane et al., 2015) and patient aggression, (McCann et al., 2015).There appears to be a paucity of research within acute in-patient psychiatric wards that care for older adults living with dementia specifically related to self-identity in dementia.

In order to determine the potential influence of the environment (acute, in-patient psychiatric) has on an individual with dementia and their self-identity, I first needed to determine whether self-identity could be measured, what validated tools could provide this information, and if it was acceptable and feasible to do so.

2.14 The Self-Identity in Dementia Questionnaire (SIDQ)

In order to address the research problem (Section 2.6), the methods introduced by Cohen-Mansfield et al. (2000) were chosen. Cohen-Mansfield's research focuses on health and mental health promotion of older persons, with an interest in environmental design and technological innovations that can improve well-being of older persons, and exploring avenues for improving their end of life experience. She has published over 300 papers in scientific journals and books, and through her research has developed a number of assessment tools and treatment approaches which are used internationally, including the Cohen-Mansfield Agitation Inventory (CMAI) and the Self-Identity in Dementia Questionnaire (SIDQ).

The SIDQ was chosen as the research study method due to its reflection of the definition proposed by Lemme (1999) that "*the self is the knowledge, feelings, and attitudes we have about our own being as unique, functioning individuals*", with particular reference to roles throughout our lifespan and development.

The SIDQ manifests aspects of the work of Sabat and Harre (1992) in that the questionnaire focuses on dimensions of self identity that cover all three types of self; Self-1, or personal identity will be highlighted through the individual completing the questionnaire whilst engaged in conversational discourse related to their self. Self-2 would be demonstrated through family and occupational roles and Self-3 would be highlighted through exploring personal attributes and what the individual considers important to them.

Finally this tool would also reflect my own stance on self-identity in dementia in that it would require creativity, innovation and positive engagement with individuals living with dementia, their informal and formal carers to be implemented. It also holds firm the belief that despite the severity of cognitive impairment, it could potentially be implemented within a new care setting, environment and care group. Lastly, this questionnaire would reflect how different people may or may not influence the individual living with dementia and how those social interactions may or may not contribute to their self-identity.

It is a valid, systematic tool for the measurement of self-identity, and is used in research studies to successfully elicit an understanding of self-identity in dementia. It is a tool that could be implemented at any stage of the illness. Many of the tools

and methods appraised for this study used self-report measures or interviews, and their MMSE (Folstein et al., 1975) scores were 18 or over. The planned study population potentially had MMSE scores much lower, and the SIDQ could be delivered by a researcher or nurse mediating any cognitive difficulties experienced by participants. This questionnaire was the only tool identified as being designed specifically for individuals with dementia focusing on their self-identity where no additional measure was required throughout a research study. It was also a multi-informant approach, involving the individual with dementia, ensuring inclusivity of those with the diagnosis and their carer or relative and formal carer.

I approached Dr Cohen-Mansfield (personal e-mail) in October 2010 to request access and use of the Self-Identity in Dementia Questionnaire (SIDQ), and a colleague, Dr Thein responded providing the three SIDQs in their original format.

Due to the methodological approach proposed by Cohen-Mansfield only being published in a few papers, never being used within a different country (only Israel) or care environment (only in nursing homes and not an acute setting or cohort of patients), a feasibility study was chosen to determine whether the SIDQ could be adapted for this purpose. This approach would determine whether the SIDQ was an appropriate tool in measuring the self-identity in individuals with dementia in an acute psychiatric in-patient setting.

Reviewing the original Self-Identity in Dementia Questionnaire (Appendix 1) raised questions about whether it would require some degree of adaptation. Cohen-Mansfield et al. (2000, p. 392) reported that from a methodological viewpoint it was

"*generally adequate*" and it was a tool that was able to elicit reliable results from a multi-informant stance with validity demonstrated (Table 5). However, aspects identified that could have posed problems included the format, wording, language, styling and overall design of the original questionnaire when looked at in relation to the general principles of questionnaire design as outlined by Rattray and Jones (2007), and Bryman (2008).

Adaptation was required to ensure that the tool could be used within a different culture, care setting, population and cohort of patients in the specific context of a secondary care environment within the NHS.

2.15 Research questions, aims and objectives of the study

(i)To what extent can dimensions of self-identity in individuals with dementia be ascertained when admitted to an acute psychiatric hospital for older adults using a culturally Adapted Self-Identity in Dementia Questionnaire?

(ii) Is the culturally Adapted Self-Identity in Dementia Questionnaire an acceptable, practical and appropriate tool for use within the clinical assessment and care of individuals living with dementia?

The Self-Identity in Dementia Questionnaire will be adapted to a suitable format for a United Kingdom population, for use within a different culture, care group and care setting.

Evaluation of the acceptability, practicality and issues of implementing an adapted format of the Self-Identity in Dementia Questionnaire within an acute psychiatric

in-patient environment will be determined. This will include the ability to recruit a multi-informant sample, application of the Mental Capacity Act (Department of Health, 2005) in research including individuals with dementia, and data collection processes.

Using an adapted version of the Self-Identity in Dementia Questionnaire, can the following be answered?

1. What are the self-identity roles that individuals with dementia identify with?

2. What is the strength of these self-identity roles?

3. What is the extent of agreement between the individuals with dementia, informal carers and formal carers about the sense of identity?

4. What, if any, are the ways that different informants think self-identity information can be elicited?

5. What, if any, are the ways that different informants perceive self-identity can be enhanced and what is the potential impact of this?

2.16 Chapter Two Summary

Chapter Two has provided an overview of the theoretical concepts of self-identity, exploring contemporary definitions of self-identity, psychological and sociological perspectives, self-identity in illness and application to dementia care.

The literature review strategy to examine measurement of self-identity within dementia was provided, outlining the qualitative studies that have explored and described self-identity dimensions, and the quantitative tools and measures that have been developed and used to investigate self-identity. This chapter provided an outline of the rationale for the choice of approach and methods, and the rationale for adaptation of the Self-Identity in Dementia Questionnaire. The chapter concluded with the presentation of the research questions.

Chapter Three – METHODOLOGICAL APPROACH AND METHODS

This chapter describes Phase One of this research study, primarily the preparatory work and planning that was accomplished to adapt the Self-identity in Dementia Questionnaire (SIDQ). It will outline the approaches used to redesign the questionnaire for use within a different country, with a different cohort of individuals with dementia and within a different care setting, describing the final development of the Adapted Self-Identity in Dementia Questionnaire (Adapted-SIDQ).

The role the Mental Capacity Act (Department of Health, 2005) had in research activities with individuals with dementia will be covered, including ethical approval application to the National Research Ethics Service (NRES) and how, following a favourable opinion, ethical considerations and implementation of the Mental Capacity Act were executed within the study.

It will then describe Phase Two of the study whereby the Adapted-SIDQ was implemented within an acute psychiatric admissions ward to evaluate its usefulness and acceptability as a research tool in a clinical setting.

3.1 Overview of methodological approach of the study

A two-phase approach was adopted to answer the research questions;

(i)To what extent can dimensions of self-identity in individuals with dementia be ascertained when admitted to an acute psychiatric hospital for older adults using a culturally Adapted Self-Identity in Dementia Questionnaire?

(ii) Is the culturally Adapted Self-Identity in Dementia Questionnaire an acceptable, practical and appropriate tool for use within the clinical assessment and care of individuals living with dementia?

Due to the exploratory nature of the study, a feasibility design was chosen to determine whether the SIDQ could be used within a different country and culture, different care environment and with a different cohort of individuals with dementia. The practicality of study procedures including the ability to recruit a multi-informant sample, application of the Mental Capacity Act (Department of Health, 2005) in research involving individuals with dementia, and data collection processes were explored.

3.2. Feasibility study

Feasibility studies are used to determine whether elements of a research study can be successfully delivered and to establish the possibility of improving an existing system or developing a new one. According to Bowen et al. (2009, p.453) feasibility studies are often used;

"*...to determine whether an intervention is appropriate for further testing; in other words they enable researchers to assess whether or not the ideas and findings can be shaped to be relevant and sustainable*".

Throughout a feasibility study, practical aspects of the research process are explored, such as whether sufficient participant numbers can be recruited or appropriate data analysis procedures applied. The framework for a feasibility study (Bowen et al., 2009) aids identification of possible concerns with design aspects of the research project, and highlights logistical challenges that may be encountered. This facilitates problem-solving, ensuring detailed planning to allow for contingency development, including the identification of worst-case scenarios. The feasibility study would review the Adapted-SIDQ in its modified format to assess its adequacy in collecting the self-identity information needed. It would also provide an indication of its usefulness as a research tool and in clinical nursing practice.

Areas of focus and lines of inquiry for this feasibility research study are summarised in Figure 3 (Bowen et al., 2009, p.454);

Figure 3 Focus areas of feasibility studies

(Bowen et al., 2009)

To evaluate how the participant group representatives reacted to the Adapted-SIDQ format and that the Adapted-SIDQ was an acceptable tool to measure self-identity in individuals with dementia.

To review how the Adapted-SIDQ could be used to evaluate its demand, by gauging participant feedback - in the adaptation phase from stakeholders, any difficulties encountered upon its completion, and whether it would be useful for collecting information related to self-identity in dementia.

To review the effectiveness of the Adapted-SIDQ from the original SIDQ, and its use with a different culture, patient group and in a different care setting through observation of its use.

To provide evidence based data which, in future, may establish whether using the Adapted-SIDQ can be integrated into the current nursing assessment systems on the acute psychiatric ward.

To determine if the Adapted-SIDQ was effective in meeting the research study objectives. It would establish if the planned standard operating procedure was as effective as it needed to be, and proposed procedures enabled data collection. Measured through observation of its implementation and any changes needed.

Acceptability To what extent is the measure judged as suitable?

Expansion To what extent can the tool be expanded to provide a new program or service?

Demand To what extent is the measure likely to be used?

Integration To what extent can the measure be integrated within an existing system?

Implementation To what extent can the measure be successfully delivered to intended participants?

Aspects of feasibility studies

Bowen at al., (2009).

Adaptation To what extent does the measure perform when changes are made for a new format or with a different population?

Practicality To what extent can the measure be carried out with intended participants using existing means, resources, and circumstances?

Whether changes to the original SIDQ are appropriate to a different culture, country, new clinical area and different population, and if the stakeholder feedback was effective in adapting the SIDQ sufficiently for use with the new cohort of patients. Evidence gathered from stakeholder feedback.

Whether the Adapted-SIDQ could be delivered within an acute psychiatric environment, determine if constraints are encountered, anticipate and problem-solve should potential issues arise throughout the duration of the study. Observations of challenges/demands documented throughout the study.

3.3 Phase One of the Research Study:

Consultation, adaptation and co-design of the questionnaire

In order to adapt the original Israeli developed SIDQ, a panel of experts were invited to participate in the adaptation process. Experts here refers to stakeholders from each of the proposed participant representative groups to review the original SIDQ as developed by Cohen Mansfield et al. (2000), specifically looking at aspects of questionnaire design. Stakeholders were to represent the proposed multi-informant participant groups from the research study; the individual with dementia, informal carers and formal carers. It was felt these stakeholders could provide valuable insights to questionnaire design elements, and facilitate the questionnaire adaptation process.

It was agreed that the stakeholder groups would be directly approached by me to attend a prescheduled meeting. The groups approached were; (i) a day therapy group for individuals with dementia, (ii) a carer group (facilitated by one of the Older Persons Mental Health [OPMH] Consultant Psychiatrists), (iii) a Registered Nurse group (both Registered General Nurses and Registered Mental Health Nurses) from OPMH in-patient services, and (iv) a dual presentation and discussion session with a public and patient research representative group called ENGAGE, supported by the University of Portsmouth. This group work closely with the Research Design Service South Central (RDSSC) to ensure that there is public and patient involvement in all aspects of health and social care research within the local NHS Trusts. Attendance at the groups was then dependent upon availability, convenience, and time released from clinical duties, and these factors determined the order of meetings, which are now outlined in date order.

3.3.1 Registered Nurse stakeholders engagement (November 2012)

As a Senior Nurse working within OPMH, I sought permission from Senior Management to approach the Registered Nurses working within the proposed research setting. Following collaboration with the OPMH Modern Matron, a teaching session was facilitated by me for all OPMH in-patient Registered Nurses on 28[th]November 2012 at 14.00hrs in a multi-function room for training purposes within the main OPMH in-patient building.

This was the optimum time to include the Registered Nurses due to the cross-over of morning and late shifts, with the maximum number of Registered Nurses on duty (within the proposed study setting this could range from 6-14 Registered Nurses including the Senior Nurses and Modern Matron). Two weeks before the meeting, a letter of invitation and copy of the original SIDQ for formal carers was sent to those nurses working within OPMH in-patients at that time. Eight Registered Nurses were available to attend the group on the day.

The letter of invitation given to the Registered Nurses prior to the meeting stated the purpose of the meeting, and I asked them to note down ideas for possible changes on a piece of card that was provided in the envelope delivered through their personal work trays. Only one Registered Nurse completed the pre-attendance task of noting potential changes for discussion in the meeting. However, the session lasted for two hours, and each aspect of the original SIDQ for the formal carer was discussed in turn. Through facilitation of the group, questions were answered on the styling, question layout, design and responses available in the questionnaire. Examples of feedback from the Registered Nurses were; "*Dismissal time, what does that mean as a cause of agitation?*", "*Need to get rid of the lists and put in boxes layout - put in a grid*", "*Questions broken into*

sections", "*Somewhere for more information to be written*", "*Too much of it*", "*We will need time to complete it*" and "*Yes/no answers, the questionnaire does not ask why*?"

At the end of the session I thanked the group members for their co-operation and input, and it was agreed that once redesigned I would approach those who attended the meeting with the reformatted questionnaire for clarification of their comments, within a similarly formatted meeting.

3.3.2 Day Therapy Group stakeholder engagement (November 2012)

A NHS Day Therapy Group for individuals with dementia was held within the main psychiatric hospital in a large city in the South of England, in a campus comprising of mental health and community services to the local population. The purpose of the service is to provide post-diagnostic support for those with dementia and their carers and relatives. It provides reminiscence groups, group therapy, education and information sharing, as well as peer support for carers. In addition, the service provides a support for those with more advanced dementia or functional illness such as depression.

The research study was discussed with an OPMH Senior Nurse colleague who managed the Day Centre. It was determined that one particular day (a Thursday) would be suitable for those with dementia to be approached to participate in the review session, as those who attended were at a mild to moderate stage of dementia. The Thursday session was due to have 14 individuals with dementia attend, along with their carers.

The Day Therapy Group was attended by me on 29th November 2012, with support from two regular members of staff (Health Care Support Workers) who were familiar with individual patients' cognitive needs and levels of understanding if additional support was required. An explanatory letter was handed to the patients and their carers, if present, detailing the process and what was required by their involvement, as well as a copy of the original SIDQ for individuals with dementia. The explanatory letter set out the purpose of the research study, specifically a request for feedback on the style, design and format of the questionnaire from attendees. There was no obligation to complete the questionnaire. The purpose of the research was verbally introduced to the attendees and the contents of the letter was read out to the group so that I could answer any questions that arose. The group ended with thanking the patients and carers for their co-operation and input. I returned to the group one week later (6th December 2012) to collect the feedback. There were three questionnaires completed by individuals with dementia returned.. Examples of feedback included; "*It is important to know what is important to me*", "The *education section needs to be tailored to the United Kingdom*", "*Condense the questions*", "*Many questions can be omitted*" and "*Overall condense to two pages maximum, preferably one page*".

3.3.3 Patient and Public Engagement (ENGAGE) (December 2012)

To provide wider, additional public and patient involvement in the study, ENGAGE, which is affiliated with the University of Portsmouth, was approached. This is a group whose role provides access "*to expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an essential part*

of the process by which research is identified, prioritised, designed, conducted and disseminated." (INVOLVE, 2014).

On 13th December 2012 the questionnaire was presented to the ENGAGE group for user involvement feedback. Due to clinical work commitments I was unable to attend this session, but one of my academic supervisors, Carole Fogg, presented the research study and requested feedback on the original SIDQ questionnaire. This included styling, question layout, design and responses available in the questionnaire. The feedback provided was invaluable and clarified key themes of the questionnaire, focusing on the question content and format rather than the questionnaire design, which the other stakeholder groups had previously provided feedback on. Examples of recommendations from ENGAGE were; "*Change the terminology of self-identity so it was clearer to individuals and relatives*", "*Do not use long lists*", "*Review relevancy of Likert scales*", "*Reduce duplication/repetition of similar job roles, activities and hobbies and personal attributes*" and "*Replace surviving ability*".

3.3.4 Dementia Carer stakeholder engagement (January 2013)

A Consultant Psychiatrist within OPMH facilitated a Dementia Carer Group on the first Tuesday of the month. Permission was negotiated to approach the group, and it was agreed that I could attend a future session on 10th January 2013 at a prearranged time (11.00hrs). Information letters explaining the objectives of the study were distributed and what taking part might involve. There were nine carers in attendance on that particular day (usual maximum 14 carers). I included a copy of the original SIDQ for informal carers. I spent time discussing and answering questions with the carer attendees for approximately one hour to clarify what I was

asking of them and provide reassurance of the process. A three-week period was negotiated to enable me to return and collect their feedback on the questionnaire.

Upon my return on 31st January 2013, verbal feedback was obtained as well as the written feedback (five questionnaires). The carers demonstrated they were a very dynamic and vocal group through their feedback, providing completed questionnaires with annotated feedback including positive critical comments on the format, layout, question style and questionnaire design as a whole. They highlighted the potential burden completing the questionnaire may have on carers. Examples of feedback from the carer representative group included positive feedback such as "*Questions well thought out*", to negative feedback such as; "*Too detailed as it stands, so quite daunting to complete*" and "*I thought the options on multiple reply questions were too many*". At this stage of the feedback process, comprehensive notes were taken for consideration of the modification of the SIDQ. I thanked the Dementia Carer Group members for their co-operation and input.

3.4 Collective public and health professional stakeholder feedback

Over three months (November 2012-January 2013) the responses from the four representative expert groups were collated. The data was synthesised and discussed with the research study supervisory team. Using research expertise, clinical knowledge and an evidence base from literature on principles of questionnaire design (Boynton and Greenhalgh, 2004 and Rattray and Jones, 2007), modifications were listed in order of importance, with four key areas highlighted requiring reformatting; overall design and delivery, questionnaire layout, question wording and content, and questionnaire responses.

The four stakeholder groups were consistent in their feedback. Participants acknowledged what the questionnaire was trying to achieve in understanding those with dementia. However, negative comments related to the lists of questionnaire responses, the perceived length of the questionnaire (Appendix 1), and the amount of time participants would need to complete it.

Due to the wealth of knowledge, experience and constructive comments provided on the specifics related to questionnaire design provided by ENGAGE, their advice was used as a focal point of synthesising the feedback, with crucial comments regarding the appeal and responsiveness of the questionnaire, with further feedback from the other stakeholders informing decision-making.

Where feasible, the original SIDQ for each of the participant groups (individual with dementia, informal carer and formal carer) were then adapted, redesigned and reformatted to address the issues and challenges highlighted by the stakeholders. Further details related to the four areas of adaptation; overall design and delivery, questionnaire layout, question wording and content, and questionnaire responses, are provided below.

3.4.1 Overall questionnaire design and delivery

Stakeholders from ENGAGE, the informal carer and Registered Nurses groups felt that the questionnaire should include a covering letter to ensure that those taking part were fully informed of the study purpose. No copy of a covering letter was included with the e-mail from Dr Thein, so it was unknown if Cohen-Mansfield et al.'s (2000) SIDQ provided this letter. Therefore, a covering letter was developed specifically for each participant group. The letter described the purpose of the research study, detailing affiliation to the University of Portsmouth and the NHS. It

provided explanation related to their invitation to participate, the study purpose and processes, and information on the right to withdraw at any time without giving a reason. It also included clear and concise instructions on how to complete the Adapted-SIDQ. My name and contact details were provided should any participant need further clarification related to aspects of the research study. The covering letter concluded by thanking the potential participant for their time in reading its contents, which was written to convey to potential participants that their opinion and input was relevant, valued and appreciated.

The original SIDQ had no participant identification on each page, so "name/code" was inserted on the Adapted-SIDQ to ensure adherence to ethical principles of confidentiality and anonymity. This detail was my suggestion to ensure the paperwork could be collated easily, prevent any confusion if sheets from the questionnaire became lost, and facilitate data analysis processes.

3.4.2. Questionnaire layout and design

Feedback from the stakeholder groups stated that there was no clear distinction between the four self-identity dimensions (job, occupation or profession, family relationships, hobbies and activities, and personality achievements, attributes or traits) resulting in a cluttered design layout.

Following this feedback, on the Adapted-SIDQ the four self-identity groups were classified into distinct sections (A to D). This was to ensure the questions appeared in logical, coherent order to facilitate completion and improve the overall appearance of the questionnaire.

The order of the questions was not altered, only their layout and presentation. However, no question numbers were provided on the original SIDQ. In the Adapted-SIDQ, each identity theme (Section A to D) was given numbered questions. This ensured there was a clear distinction between questions, with smooth readability transition between questions and signposting to subsequent sections. This was in accordance with the recommendations of Rattray and Jones (2007, p.237) who state there should be a "*psychological order*" with questions on one subject, or one particular aspect, such as a component of self-identity, which should be grouped together. When one question was logically dependent upon another, every effort was made to place both on the same page and questions were not split across pages.

The questions in the Adapted-SIDQ were printed in the same font and typesetting, with font size of 11-14 used, as it was anticipated that respondents may have visual impairments. Boynton and Greenhalgh (2004) recommend the creative use of space and typeface in questionnaire design, and provide comprehensive guidance on cover design, placement of questions within pages, and question and response category formats. Therefore, to aid signposting, each question appeared in bold text with answer sections in normal font, to differentiate between sections of the questionnaire. Consistency of text and typeface were maintained throughout the questionnaire (Health Technology Assessment, 2001) since this has been identified as positively influencing respondent acceptability of a questionnaire.

It was identified from the stakeholder feedback that there was no space to provide additional comments. A free text box at the end of the Adapted-SIDQ questions specified "*Other*" or "*Additional comments*" facilitated the participants ability to provide additional information if preferred. It was important to provide adequate

space for the participants to add their own thoughts or comments that were not captured by the response categories. Stakeholders responded that the original SIDQ format of "lists" of potential question responses was uncomfortable to read and answer, as the lists were detailed over several pages. In the Adapted-SIDQ, the participant choices were tabulated for participants to indicate their response preference. This change would facilitate the completion of the questions, as it was less complicated and more user-friendly.

3.4.3 Questionnaire wording and content

Bryman (2008) suggests that the language used in questionnaires should avoid ambiguity and jargon, ensuring understanding by participants. The ENGAGE group were particularly vocal about the use of language throughout the original SIDQ, highlighting cultural differences that needed to be addressed:

•   Under a job, occupation or profession related question in the original SIDQ, the questions stated "*security/law enforcement*"; it was suggested that the wording be changed in the Adapted-SIDQ to replace "*enforcement*" with "*police*" and thus stated "*security/law/enforcement/police*" to ensure relevant occupational descriptors commonly used in the United Kingdom.

•   Under family role in the original SIDQ, it stated "*being a spouse*". Based upon feedback, the Adapted-SIDQ stated "*being a husband or wife*" as appropriate. Whilst spouse refers to a life partner and is gender neutral, it was felt that spouse is rarely used and "husband or wife" was more appropriate to facilitate understanding, particularly for those participants with cognitive impairments.

- In the original SIDQ, under hobbies and activities, several of the options listed had similar themes but were listed separately. The stakeholder feedback suggested a few of the hobbies and activities should be clustered, for example *"trips outside/days out"*. Grouping the hobbies and activities in this manner facilitated the tabulated format of the response options available, reducing the long lists in the original SIDQ.

3.4.4 Questionnaire responses

The original SIDQ used a seven-point Likert scale to measure responses on the importance of self-identity. Considering the advice from ENGAGE, this was changed to a five-point Likert scale for more concise options to gauge participants' strength of importance on self-identity. It was postulated that a five-point scale would be less complicated for the participants, as the original SIDQ had several answers on the scale making it difficult to differentiate between choices, for example *"not relevant"* and *"not at all important"*. Specific questions from the Adapted-SIDQ had a five-point Likert scale but a further option of *"unable"* was provided. This was felt to be an important addition by the Dementia Carer Group to accommodate those individuals with dementia who were experiencing impaired communication. The change of Likert scaling would be unlikely to influence the validity of the self-identity measurement as it would still be measuring the construct of self-identity, just on a smaller scale (Krosnick and Presser, 2010).

3.5 Final questionnaire completion; The Adapted Self-Identity in Dementia Questionnaire

There were limitations in time and an inability to contact the original participants from all the stakeholder groups. This was due to patients from the Day Centre

suffering from deterioration in their illness inducing admission to residential care homes, staff members leaving the OPMH service, and inconsistent membership in the ENGAGE group, so it would have been challenging to contact the original individuals who provided feedback. However, feedback on the Adapted-SIDQ was sought from two Registered Nurses within OPMH who had been in the original focus group.

This feedback was to refine and develop the questionnaire once in its redesigned format. They were asked to complete the questionnaire with hypothetical patients with dementia in mind so they could evaluate the covering letter and instructions. This was to identify any major flaws with the questions, but in particular they were asked to review its readability, if the questions were in the best order, to determine any difficulties with answering the questions, if there were any they felt that they could not answer, if there were any blank spaces, and how long the questionnaire took to complete. For the Registered Nurses, this took 17 minutes and 23 minutes. Additional time was provided for both the individuals with dementia and their informal carers, with the instruction letter for all participant groups stating it would take approximately 20-30 minutes of their time to complete.

Despite provisional ethical opinion being granted for the research study in July 2012, on 1st February 2013 the final version Adapted-SIDQ and associated paperwork were resubmitted to the NRES Committee as a substantial amendment to the original application. Final favourable ethical opinion was granted for the study to commence fully from 15th March 2013. The Committee were satisfied that there would be no additional risk to the potential participants with the adapted format of the SIDQ, justification for changes was accepted and would all be in the

best interests of those involved in the study, and the associated paperwork was confirmed as appropriate for the aims of the study.

The Adapted Self-Identity in Dementia Questionnaires can be seen in Appendices 3; for the individual with dementia, Appendix 3 (i), for the informal carers, Appendix 3 (ii) and for the formal carers, Appendix 3 (iii).

3.6 Ethical considerations in relation to study methods

The National Dementia Strategy (Department of Health, 2009a) introduced a strategic framework which aimed to address three fundamental areas: "*improved awareness, earlier diagnosis and intervention and high quality care*" (Department of Health, 2009a, p.9). The strategy emphasised the need for evidence-based interventions for those with dementia through a coordinated research programme (Department of Health, 2009a, Objective 16).

However, according to Hellstrom, Nolan, Nordenfelt and Lundh (2007) people with dementia continue to be one of the most excluded groups in society based upon two factors: age and cognitive decline. These entrenched issues reinforce that individuals with dementia rarely have their voice heard with regard to their illness, treatment and care. The rationale for this exclusion is complex. One possible explanation is that traditional ethical principles, when applied to dementia research, do not appear appropriate as they are limited in scope and flexibility. Hek and Moule (2006) outline four fundamental principles of ethical governance that need to be adhered to in order to protect potential participants in research. These include the principles of veracity, justice, beneficence and respect. They accentuate the need for informed consent to be obtained in writing following consultation with participants, but this lack of flexibility potentially excludes people

with dementia and the adequacy of these ethical guidelines are questioned (Loff and Black, 2000).

Perceptions of health and social care practitioners when safeguarding vulnerable people such as those with dementia may act as a barrier to participation in research. Historically, consent to participate in research activity has been sought from a carer or relative of someone with dementia. An example is provided by Cacchione (2011) in her study where "*consent by proxy*" (authorisation from another person to act on the behalf of someone else) was used to involve those who did not have the capacity to consent. However, this research was conducted in Canada, where the Mental Capacity Act (MCA, Department of Health, 2005) is not legislation. The Government of Ontario have the Health Care Consent Act (1996), however this does not cover research activities in any detail. Throughout earlier studies there was an assumption that the proxy's decision making was based upon the wishes of the individual for whom they were consenting (Bravo, Paquet and Dubois, 2003). However, this approach is now considered outdated and not in-keeping with a person centred, inclusive methodology.

Beach et al. (2005) argue that proxy decision making limits true autonomy, but the ethical principle of respect for an individual is more complex than just autonomy. It includes interrelated concepts such as dignity and individuality of the person, central to which is the duty to protect patients whom cannot themselves make autonomous decisions. This premise is fundamentally linked to the need for best interest considerations under the Mental Capacity Act (Department of Health, 2005) to include the person's past and present wishes and feelings, any beliefs or values that would be likely to influence the decision-making process if they had capacity, and any other factors they would have considered if able to do so.

Lastly, the assumed challenges involved in applying for and gaining favourable ethical opinion for research studies that involves those individuals who lack capacity to consent often acts as a barrier to researchers. This is due to the perception that ethical approval will be declined on the basis of the nature of the illness. However, this perception is inaccurate and the guidance available in the Mental Capacity Act (Department of Health, 2005) ensures that all aspects of any research studies are designed to include those with dementia in a safe, transparent framework.

3.6.1 The Mental Capacity Act (Department of Health, 2005)

The Mental Capacity Act (Department of Health, 2005) was introduced in the United Kingdom to ensure that those people who lacked the capacity to make decisions for themselves were given a statutory framework to support, guide and protect them. It outlines who can make decisions, in what circumstances and how to do this is. According to the Mental Capacity Act (Department of Health, 2005), where an individual's capacity to make a decision is to be determined, the two stage test of capacity must be completed with regard to a specific decision (Figure 4). The capacity assessment should not be based upon age, diagnosis or condition, appearance or behaviour (MCA Code of Practice, Department of Constitutional Affairs, 2007), and the types of decisions that are involved range from every day decisions, such as what to wear, through to major decisions that may have a significant impact on their lives, such as future health, welfare and financial decisions.

Health and social care practitioners must not treat the individual with dementia as unable to make a decision just because they make a decision they do not agree

with; the individual has the right to make unwise decisions. It is not on the basis they are diagnosed with dementia that they would be deemed not to have capacity. It is not a question of whether the individual can "do" one or more of the two stage test, but more a process by which they are given the opportunity to decide and are supported with decision making.

Stage 1	•Is there an impairment of, or disturbance in, the functioning of a person's mind or brain?
Stage 2	•Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?
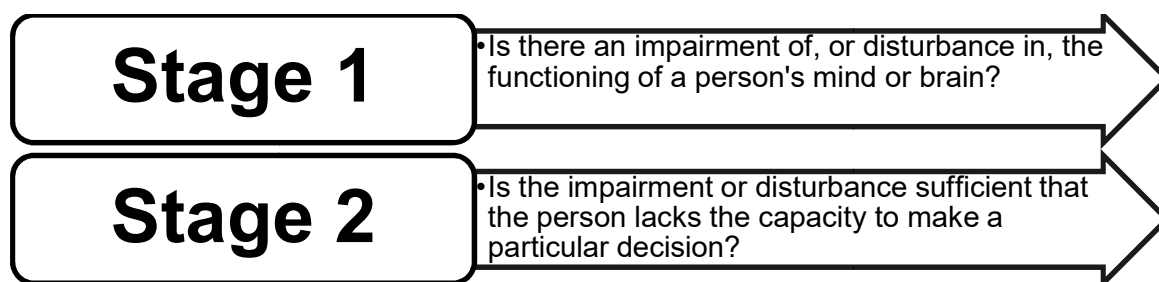
Throughout Stage Two when determining capacity to make any decision, four viewpoints need to be taken into consideration:

Does the individual **Understand** the information? Every effort must be made to enable the individual to understand the information related to the decision.	**Retain** that information long enough to be able to make the decision. If the individual is able to retain the information even for only a short space of time to make the decision, this must be taken into account. There must not be an assumption that they lack capacity. They may be able to retain the information but not communicate the decision so facilitation of this will be required.	**Weigh** up the information available to make the decision. To weigh up the information provided involves the individual to understand the positive and negative aspects related to the decision to be made. These need to be provided for the individual in a format that will enable their understanding. Once more, time needs to be given to allow them to weigh up these points.	**Communicate** their decision. Many people with dementia can verbally state their views. However, for those with complexities associated with neurological and cognitive impairments, additional support will need to be accessed.

Figure 4 Assessment to determine capacity as per Mental Capacity Act (Department of Health, 2005)

3.6.2 The Mental Capacity Act (Department of Health, 2005) with regard to research activities

The MCA (Department of Health, 2005) acknowledges the importance of research activities for those who lack capacity or encounter illnesses where capacity either fluctuates or is lost. It is Sections 30 - 34 of the MCA (Department of Health, 2005) that focus on research involving those individuals who potentially lack the capacity to consent to participate.

The MCA Code of Practice (2007, p.202) summarises what the Mental Capacity Act (Department of Health, 2005) covers:

• When research can be carried out

• The ethical approval process

• Respecting the wishes and feelings of people who lack capacity

• Other safeguards to protect people who lack capacity

• How to engage with people who lack capacity, with their carers and other relevant people.

Sherratt, Soteriou and Evans (2007, p.470) state "*capacity and consent need to be addressed simultaneously rather than as discrete processes*" and they recommend developing a specific assessment tool for the research study to determine capacity to consent, which reflects the need for a complimentary approach which includes both aspects. Any tools used must be based upon the two stage capacity test (Figure 4) in order to meet the requirements of the Mental Capacity Act (Department of Health, 2005). The individualised approach of

Sherratt et al. (2007) was adopted as part of the capacity and consent processes for this study (Appendix 2).

If an individual understands the research aims, is able to retain the information given regarding participation, can judge the risks and benefits of being included in the study, and can communicate to a researcher they are willing to participate, the individual is deemed to have the capacity to consent. If in agreement, they can sign a research study consent form and participate as required.

If deficits are identified throughout the assessment process, the researcher should consider the person's mental state at the time, determine if their impairment fluctuates, ask is there is a better time of day to assess the person or enquire if the information presented is in the most unambiguous way possible for that person. The researcher may need to consider revisiting methods of enabling understanding for participants to ensure they comprehend the research to provide consent. If all avenues of facilitation have been exhausted, there will need to be a final decision made that the individual does not have the capacity to consent to participate in the research activities.

A researcher can enquire whether a potential participant has an advanced statement, direction or care plan which may be applicable to research activities. These are important documents for safeguarding an individual's interests and rights to personal choices and decision making.

According to the Mental Health Alliance (nd, p.3);

"*Section 4(6)(a) of the Mental Capacity Act explicitly states that when determining a person's best interests when that person lacks capacity, any written statement made when they had capacity should be considered*".

If the individual has an advanced statement, a copy can be requested from whoever holds that statement to facilitate the consent processes for their potential participation in research. If it is deemed that the potential participant does not have the capacity to consent to participate, their involvement must meet one of two criteria: the research must have some benefit to the person who lacks capacity, and aim to provide knowledge about the cause of, or treatment or care of, people with the same illness or condition. In addition, a Consultee will need to be identified as per Sections 30-34 of the Mental Capacity Act (Department of Health, 2005). A Consultee is a Personal Consultee, someone whom the perspective participant knows, such as a relative, carer or someone who has Lasting Power of Attorney (LPA) for health and welfare, or a Nominated Consultee. This role is invoked if the potential participant has no family or carer, or the relative does not feel that they can take on the responsibility associated with the decision, such as a solicitor, GP or Independent Mental Capacity Advocate (IMCA, Department of Health, 2009b).

3.6.3 Application to National Research Ethics Service (NRES)

During Part Two of the Professional Doctorate in Nursing programme, a research skills study day was attended (September 2011) focusing on the practical use of the Integrated Research Application System (IRAS), the online application system for NHS ethical approval for all research projects in the United Kingdom.

IRAS provides a single electronic process for applying for permission and gaining approval for a research study conducted within the NHS, which negates the need for duplicating identical information on separate application forms for NHS Research and Development approval at the NHS specific site(s),where the research will be conducted.

Consideration was given to ensure the submitted application adhered to sound ethical principles.

As the Senior Nurse, leading and managing the clinical area where the research study was conducted, ethical issues needed consideration prior to the implementation of the study. Professional socialisation has ingrained a belief that the welfare of my patients is at the forefront of my practice, yet there was potential for conflict due to my commitment to the advancement of knowledge through research.

Colbourne and Sque (2004, p. 297) described the "*split personality*" that is adopted when examining the conflict that emerges when adopting a research role whilst working as a clinician, yet Yanos and Ziedonis (2006) state that clinician-researchers serve as effective "*bridgers*" between the research community whilst facilitating the development of clinically relevant research and the dissemination of evidence-based nursing practice. They go on to describe "e*xternal and internal role confusion";* external role confusion arises when the clinician-researcher attempts to clarify for others what their job really is. Internal role confusion results from research and clinical work consisting of different "*ways of being*" in a work environment. Being a Senior Nurse who fluctuated between these two types of

work there was a constant adjustment in mind set between the different roles and responsibilities.

Holloway and Wheeler (2002) suggest that to achieve balance there is a need to maintain an investigational focus and not adopt an educational, nor counselling role as these could introduce bias. However, to detached myself from these critical aspects of a Senior Nurse in a leadership and management role would not be in the best interests of my staff nor for the study.

I held a position of authority, where "*power asymmetry*" was a risk (Hamberg and Johansson, 1999), and "*employees are likely to view their employers as authority figures to whom they must show deference*" Department of Health and Human Services (2011).

This could have led to a perceived risk of coercion of the Registered Nurses in this setting, with my nurses feeling obliged to be involved in my research study. It raised questions as to whether they could exercise autonomous choice. Yanos and Ziedonis (2006) recommend the full disclosure of potential conflicts to research participants to deliver the message that there will be no conflict between my role as clinical and researcher. The team were explicitly made aware that participation was voluntary, would not affect their job roles and responsibilities, and their refusal to participate would not result in detrimental employment conditions. The Registered Nurses' autonomous decision to participate in the research was sought following an education session explaining and discussing of their role and responsibilities in the study, if they chose to take part. Making myself accessible for opportunities to ask questions were provided including an open

invitation to approach me at any time they had additional queries, yet I found my nurses very open to research and to new ideas.

However I was aware that through participation, the Registered Nurses would be adding to their already excessive workload, yet I hoped these risks would be mediated through regular monthly clinical supervision, weekly team meeting discussions and informal 'catch ups' when required. This in turn would communicate to my staff that I was preserving their trust in me as their Senior Nurse by protecting and supporting them when required.

Being purposefully restricted to either a clinical or research day would have proven to be too much of a barrier to my nursing team, and I do not think that would have helped progress the research process or support them. Through adopting a flexible approach to the dual role, ethical principles were upheld.

I questioned my ability to remain unbiased, but I recognised and acknowledged my personal values and prejudices, whilst seeking to integrate my dual roles and aimed to develop a *"coherent moral identity"* (Miller et al., 1998) that promoted good ethical judgment and self awareness of how my actions may influence participants. Balance was achieved through developing an integral clinical and research identity, honestly and sensitively disclosing my roles and not hiding the fact that I was a nurse. Throughout the study, I was so often called on to unitise the skills that I have developed through my mental health nursing practice to achieve the desired outcome of the research and to continue supporting my staff not only through the project, but through day to day clinical care of our patients.

Including participants with a diagnosis of dementia, I needed to consider carefully how I could ensure that everyone was informed fully and participating voluntarily.

These ethical considerations were made with guidance from the Trust Mental Health Act/Mental Capacity Act Lead, and reliance upon my clinical knowledge, experience and judgement.

Whilst populating the required elements of the NRES application form for the research study, it was identified that due to the nature of the participants included in the study, in that they have a diagnosis of dementia, a clear process of how to assess capacity to consent and the risks involved in their association with the study could be adequately addressed based upon earlier considerations. Research involving participants who potentially lack capacity under the guidance of the Mental Capacity Act (Department of Health, 2005) is still a relatively new area.

Preparatory work was conducted to ensure the appropriate measures were in situ to support those who potentially lacked capacity and minimise any risks involvement in the study would pose. This included the development of an assessment proforma to determine capacity to consent. Due consideration was given to the type and format of information presented to enable comprehension to ensure meaningful informed decision, and that any consent form used language and a format appropriate to those with cognitive difficulties of different severities. Inclusion of the use of Personal Consultees was also considered and included in the NRES application, as well as the standard operating procedure (SOP, Figure 5, Section 3.8) for the implementation of the study to ensure that a consistent approach was applied. Table 6 lists the paperwork that was submitted with the NRES application. Full copies of the paperwork can be seen in Appendices 2 to 4.

Table 6 Submitted paperwork to National Research Ethics Service related to the research study

Forms submitted – General	Forms submitted for ethical consideration in relation to the administration of the Adapted Self-Identity in Dementia Questionnaire
IRAS application form Research proposal for Professional Doctorate in Nursing, University of Portsmouth Personal Curriculum Vitae for Aileen Murray Academic Supervisors Curriculum Vitae x 2 Baseline Information Sheet for Self-Identity in Dementia Study Mini Mental State Examination Barthel Activity of Daily Living Index Notification to Consultant Psychiatrists Standard Operating Procedure for Consent Processes	Mental Capacity Assessment for Consent to Participate in the Proposed Research Project Your life story – Information Sheet for Participants with Dementia Consent form for Participants with Dementia Information Sheet for Informal and Formal Carer Participants Recruitment Letter for Informal and Formal Carer Participants Sample Letter to Personal Consultee Information Sheet for Personal Consultees Self-Identity in Dementia Questionnaire – Nursing home resident Self-Identity in Dementia Questionnaire – Nursing home family Self-Identity in Dementia Questionnaire – Nursing home staff Adapted-SIDQ for Individual with Dementia Adapted-SIDQ for Informal Carer Adapted-SIDQ for Formal Carer

The original submission date to NRES was 21st June 2012, which resulted in an appointment to attend the NRES Committee South Central meeting in Southampton on 10th July 2012. It was acknowledged at the meeting that as the principal researcher, my current role and experience showed a clear understanding of the Mental Capacity Act (Department of Health, 2005) and how to support individuals that may lack capacity to consent in an ethical manner. The ethical review panel of the committee felt that the sample letters were "*confusing and complicated*", and that the consent form for participants with dementia needed to be "*simplified*" further (Appendix 2). Questions raised from panel members focused on the issue of timing, that 24-48 hours was not sufficient time for the consent processes to be implemented across the three participant groups. Reassurances were provided that a flexible approach and more time would be

facilitated when required. The NRES Committee also considered the SIDQ in its current format, concluding the need for modification to apply to a United Kingdom audience, and it was explained that this was the intention of Phase One of the feasibility study.

Provisional opinion from the NRES Committee was granted on 23rd July 2012. Due to the issues raised regarding aspects of the paperwork consent processes, the invitation letters and consent form for participants with dementia were redesigned, and the panel required a copy of the post-adaptation version of the SIDQ. These were resubmitted as a substantial amendment on 1st February 2013. Final favourable ethical opinion for the research study to proceed was granted on 15th March 2013. The University of Portsmouth UPR16 Ethics Form was also submitted (Appendix 4).

3.6.4 Implementation of the principles of the Mental Capacity Act (Department of Health, 2005) to the Adapted Self-Identity in Dementia Questionnaire

The mental capacity assessments conducted with the individuals with dementia prior to the Adapted-SIDQ were designed by me based upon guidance from the British Psychological Society (2008), my own academic and clinical knowledge, and experience within mental health nursing practice and dementia care. The assessment forms developed were effective in establishing whether the potential participant had an impairment of mind or brain which may have impacted on their ability to understand the research project, weigh up benefits and risks of the study, and communicate this decision to enable the capacity related decision to be made. It was successful in determining if the participants with dementia had the capacity

to provide informed consent to be included in the study. The following strategies were used to facilitate consent processes for those participants with cognitive impairment:

<u>Revisiting potential participants</u> - For those who had undertaken the mental capacity assessment and whose capacity to consent was in doubt, reassessing their capacity on other occasions was required. Capacious decision making for the majority of individuals with dementia (n=10/15) was reconsidered to ensure that they understood the project and were able to clearly provide consent to participate. The remaining five participants were able to consent once information was provided. For three participants, revisiting them on more than two occasions was required where simplified explanations of what was required of them facilitated their understanding and subsequent consent being obtained. This was either conducted on the same day or subsequent days.

<u>Change of environment</u> - A change of environment was helpful for some participants. Being taken from the busy ward environment and spending time with me in a quiet, undisturbed area (private bedroom or activities room) where they could concentrate and distractions were reduced helped to facilitate understanding and establish their capacity to consent to participate.

<u>Flexible one to one time</u> - The challenges that individuals with dementia face when experiencing complex concepts and communicating these to others was clear when implementing the questionnaire. One participant became very angry stating "*I hate all these stupid questions*!" When faced with direct questions, individuals can feel threatened or cornered, as it has a negative impact on their coping mechanisms when trying to answer questions they find hard to grasp or work out

answers to. One patient from this study became very frustrated at themselves when trying to answer the questions posed. I tried not to induce an atmosphere of being "assessed", creating an environment where we could explore their thoughts and feelings about the research study in a relaxed manner where they did not feel pressurised. This was of paramount importance, which facilitated the consent process and completion of the questionnaire. When the individuals with dementia displayed signs of distress or anxiety regarding the process, they were reassured and I withdrew as per the ethical guidelines of the study. Support for the individual was then sought from a Health Care Support Workers (HSCW) as per the Standard Operating Procedure, as the Registered Nurses were identified to complete the Adapted-SIDQ; the HCSW maintained their supportive role.

The mental capacity assessment tool used for this project (Appendix 2) was individualised and sensitive to the needs of those participating, highlighting the effectiveness of a flexible person centred approach to assessing capacity for consent processes in clinical research including persons with dementia.

<u>Physical and sensory limitations</u> - Contracted hands through arthritis or poor eyesight meant that some individuals with dementia were not able to complete aspects of the Mini Mental State Examination (MMSE, Folstein et al., 1975) including shape drawing or writing the required sentence and signing the consent form. The MMSE was calculated to take these limitations into consideration as required, following guidance from Dean, Feldman, Morere and Morton (2009) regarding hearing impairments and Busse et al. (2002) for those with visual impairment. The consent forms were signed by the researcher, with participant signatures preceded by p.p. (per procurationem), an indication to any reader that the form was signed on behalf of another.

<u>Pictorial paperwork</u> - There was a high degree of sensory and physical impairments, which detracted from the traditional approaches needed to gain written consent, posing a great challenge in assessing capacity to consent to participate. For example, one participant suffered from hearing impairment, and he had non-functioning hearing aids, so there was a need to use the pictorial consent information to facilitate understanding. Assessing the person's sensory and physical abilities throughout the initial stages of the process allowed choice of an appropriate format based upon need. Using different formats developed for the consent of individuals with dementia such as using a pictorial consent form (Appendix 2) or reading the information to the individuals with dementia was beneficial, but this varied depending on each person invited to participate.

<u>Reading information</u> - The participants with dementia were given the opportunity to read and/or view the pictorial information sheet specifically designed for them (Appendix 2). Most were able to read and understand the simplified information sheet about the project or this was read to them, which led to an opportunity for questions to be clarified and further discussion regarding the study to take place.

<u>Relative's presence or awareness</u> - Relatives being present throughout the capacity assessment provided emotional support for the individuals with dementia, and the consent process was effectively implemented. Also, by informing those with dementia that their relatives were aware that the questions were being asked appeared to reduce potential additional confusion or anxieties this could induce for the individuals with dementia.

<u>Behavioural and Psychological Symptoms in Dementia (BPSD)</u> - There were no participants excluded from the study on the basis of BPSD as per the study inclusion and exclusion criteria.

<u>Physical health concerns</u> - One participant was not able to be included in the consent process due to poor physical health, and subsequent transfer to the general hospital for treatment. Consideration of physical health is essential due to the potential impact it has on the mental health of the individuals with dementia, and the risk of further cognitive impairment through delirium.

<u>Personal Consultee</u> - Two potential participants where their capacity to consent was a concern led to the process of approaching Personal Consultees as per the study Standard Operating Procedure (SOP) for consent processes (Figure 5). The relatives of the individuals with dementia were approached. One Personal Consultee was able to determine that their sister would have liked to have participated in the study prior to losing capacity to consent, but the informal carer expressed concern as to the anxiety and distress it would invoke being asked many questions, and felt it would not be in her best interests to do so; therefore the patient was not included. The second informal carer approached to be a Personal Consultee stated that their relative would have agreed to participate in the study prior to their capacity being lost, and did not believe that through participating there would be any anxiety or distress caused, thus their inclusion in the study.

3.7 Phase Two of the Research Study:

Implementation of the Adapted Self-Identity in Dementia Questionnaire

A full description of the study setting, participant inclusion and exclusion criteria, participant groups and characteristics, recruitment and consent processes, and data handling and analysis processes for the Adapted-SIDQ will be provided.

3.7.1 Study setting for use of the Adapted Self-Identity in Dementia Questionnaire

The study setting for the administration of the Adapted-SIDQ was within a psychiatric hospital in a large city in the South of England. The hosting NHS Trust was created in 2011 and serves a population of over 1.5 million people. It specialises in providing community and mental health services to people living in Portsmouth, Southampton and parts of Hampshire, with over 100 clinical sites, spread across the area, employing over 3,500 staff.

Within the community and mental health campus there is a 36-bedded OPMH unit. Housing three wards, it is a purpose built in-patient facility opened in 2009 following consultation with previous patients, relatives and carers, and health care professionals as to the needs of this patient cohort. Those admitted to the unit are older adults (male and female) with a functional illness, older adults with an organic illness or patients under 65 years of age with some form of dementia, providing crisis intervention to treat, manage and meet complex mental health needs through in-depth clinical assessment for those who are vulnerable and at risk in the community.

Ward A, the main study site, is one of three OPMH wards situated within this building. There is a14-bedded assessment ward (Ward B) for functional mental

health problems in later life such as depression, anxiety and psychosis, and the other is an 8-bedded ward (Ward C) caring for those with a severity of dementia where the person is unable to be placed in a community setting due to the complexity and intensity of their illness and palliative care provision required.

Ward A is a 14-bedded residential acute psychiatric admission ward providing assessment of dementia and treatment of the symptoms associated with the illness. People with dementia are admitted to Ward A for the following reasons; (i) a severe deterioration in their condition such as the development of behavioural or psychological difficulties, (ii) following diagnosis of a co-existing mental health problem such as depression, or (iii) a crisis in care provision.

Table 7 Nursing staff structure in study setting for Adapted Self-Identity in Dementia Questionnaire

WARD A – Organic Assessment Ward Maximum 14 patients	WARD B – Functional Assessment Ward Maximum 14 patients	WARD C – Continuing Assessment Ward Maximum 8 patients
1 x Band 8 Modern Matron (RGN/RMN)		
1 x Band 7 Senior Nurse (RMN) who co-manages Ward C	1 x Band 7 Senior Nurse (RMN)	
1 x Band 6 Deputy Senior Nurse (RGN and RMN)	1 x Band 6 Deputy Senior Nurse (RMN)	1 x Band 6 Deputy Senior Nurse
6 x RMN or RGN	6 x RMN	5 x RGN or RMN
14 HCSW	12 HCSW	10 x HCSW

Table 7 summarises the staffing levels within the study setting. The OPMH unit is staffed by registered mental health and adult (general) nursing staff, as well as Health Care Support Workers (HCSW) and host/hostess staff who manage the in-house catering for the patients. Wards A and C are managed by a Band 7 Senior Nurse with a Band 6 Deputy Senior Nurse, and Ward B has a Band 7 and Band 6 nurse. The overall management of the three wards is the responsibility of the

Modern Matron. In addition to the three wards, there is a team of administrators and allied health professionals including Occupational Therapy and Physiotherapy staff. Three Consultant Psychiatrists work within OPMH, each with a Foundation Doctor to assess and treat both the physical and mental health needs of the patients. The multi-disciplinary team complete physical and neurological examinations, cognitive tests, assessments of function and behaviour, nursing assessments of patient health needs, identification of psychosocial and pharmacological treatment and support interventions. Length of stay is determined by individual need, response to treatment and care pathway upon discharge. As a mental health service, OPMH has seen length of stay figures increase (calculated average stay 75 days, April 2015). This can range from two weeks to a year or longer if the need arises.

The Mental Health Act (Department of Health, 1983, amended 2007) is used within the study setting for formal detention in a hospital for the assessment and treatment of mental illness.

The Mental Capacity Act (Department of Health, 2005) is also applied in all aspects of the individual's care, from admission and treatment decisions to clinical interventions and discharge planning. For patients who are assessed to be Deprived of their Liberty (DoL) in line with the Mental Capacity Act (Department of Health, 2010), safeguards are implemented to maintain their rights. Upon discharge from Ward A, depending upon their ongoing needs, the individual with dementia can be discharged home, or into residential or nursing home care with support and follow up from their Consultant Psychiatrist, Community Psychiatric Nurse(CPN) or other member of the multidisciplinary team which is felt appropriate to meet ongoing needs.

3.7.2 Inclusion and exclusion criteria for each participant group for the Adapted Self-Identity in Dementia Questionnaire

Table 8 outlines the inclusion and exclusion criteria for each participant group included in the study, which were different for each participant group, but all interdependent upon each other. If the individual with dementia was unable to participate, the remaining two groups could not contribute due to the multi-informant nature of the study design.

Table 8 Participant inclusion and exclusion criteria

Participant group	Inclusion criteria	Exclusion criteria
Individuals with dementia	Admitted to the acute psychiatric assessment ward. Confirmed diagnosis of any form of dementia and any severity (mild, moderate or severe). Medically stable. Able to understand and speak English. For whom consent can be obtained, through the individual or Personal Consultee.	Severe behavioural or psychological difficulties that pose a significant risk to him or herself, or the researcher. Un-befriended, no next of kin or informal carer.
Informal carers	Carer meets the individual with dementia eligibility criteria, as above. Known the person with dementia and their past for a minimum of five years in order to answer the questions posed in the Adapted-SIDQ. Signed informed consent.	If individual with dementia unable to participate.
Formal carers	The Registered Nurse will be registered with the Nursing and Midwifery Council (NMC). The Registered Nurse works as the patient's Named Nurse (their key worker responsible for the co-ordination of all nursing care). Named Nurse for one or more individuals with dementia included in the study. Signed informed consent.	If individual with dementia and informal carer unable to participate. Working permanent night shifts.

3.8 Recruitment of study participants for the Adapted Self-Identity in Dementia Questionnaire

The target population for this study were individuals diagnosed with dementia (Alzheimer's disease, Vascular Dementia, Lewy Body Dementia or other forms of dementia) and admitted to the acute psychiatric in-patient assessment ward (Ward A). All those diagnosed with dementia met the criteria as detailed in the ICD-10 Classification of Diseases (National Institute for Clinical Excellence/Social Care Institute for Excellence, 2007). In addition, their informal carer or relative were invited to participate, as well as Registered Nursing staff in the role of formal carer of those with dementia.

For this study, it was anticipated that 60 participants in total, to provide 20 complete data sets for analysis, would be required. Hertzog (2008) stated that the sample numbers for a feasibility study could be as low as 10 to 15 participants. However, it was decided that increasing this number to 20 participants: 20 individuals with dementia, their informal carer (20) and formal carer (20) would provide for incomplete data sets or participant withdrawal. The sample was taken from a whole population sample of all those patients admitted to the ward and eligible to take part. Reviewing historical data available from Ward A over a ten-week period from January 2011 to mid-March 2011 there were 16 admissions. It was estimated that over the span of six months there would be sufficient participants for the feasibility study and review of the Adapted-SIDQ.

Due to the complexities associated with recruiting people with dementia and their carers for the study, a standard operating procedure (SOP, Figure 5) was

developed to ensure clear guidance to support the study recruitment stages. Recruitment commenced at the beginning of July 2013 and ended in July 2014.

Once the individual with dementia met the study inclusion criteria, a mental capacity assessment (Appendix 2) was conducted to determine if they had the capacity to consent to be involved. If they did, the consent form was signed and the background details of the patient documented. This included reasons and circumstances surrounding admission, Mini Mental State Examination (MMSE, Folstein et al., 1975) and Barthel Activities of Daily Living score (developed by Mahoney and Barthel, 1965 and revised by Collin, Wade, Davies, and Horne, 1988). The Adapted-SIDQ was then completed with the individual with dementia. Informal carers were approached inviting them to participate in the study. If they agreed, the consent form was signed and the Adapted-SIDQ for the informal carer completed. Lastly, the Registered Nurse was asked as the formal carer to complete the Adapted-SIDQ within two weeks of the patient's admission.

If the patient was deemed to lack the capacity to consent to participate in the study, their informal carer was approached to perform the role of Personal Consultee. This is the process whereby a researcher consults an individual close to the potential participant to determine if, prior to the illness that caused loss of or fluctuations in capacity, the individual would have wanted to participate in a research study. If the Personal Consultee felt that the individual with dementia would have wanted to participate, the appropriate study forms and Adapted-SIDQ were completed.

If the individual with dementia had no next of kin or informal carer they were omitted from the study, as the Adapted-SIDQ required a multi-informant approach

with all three questionnaires being completed across all three participant groups. If a person with dementia was "un-befriended" (no close friend, relative or carer), the Adapted-SIDQ could not be completed.

There were three separate participant recruitment pathways to achieve multi-informant (individuals with dementia, informal carers and formal carers) completion of the Adapted-SIDQ. For each participant group, participant characteristics and process implementation of the study are described below in Figure 5.

INDIVIDUAL WITH DEMENTIA ADMITTED TO WARD

NURSING STAFF ESTABLISH IF PATIENT MEETS INCLUSION CRITERIA

DOES NOT MEET INCLUSON CRITERIA

EXCLUDED FROM THE STUDY

PATIENT HAS CAPACITY TO CONSENT

INDIVIDUAL WITH DEMENTIA CAPACITY ASSESSMENT AND CHECKLIST WITH REGARD TO RESEARCH PARTICIPATION

PATIENT LACKS CAPACITY TO CONSENT

PATIENT INFORMATION SHEET AND CONSENT FORM

REVISIT PART 2 OF THE 2 STAGE TEST OF CAPACITY

NO FAMILY OR "UNBEFRIENDED"

FAMILY, CARER OR POWER OF ATTORNEY

CHECK FOR ADVANCED DIRECTIVE FOR WELFARE

PATIENT WITHDRAWN AS PART OF EXCLUSION CRITERIA

ADMINISTER ADAPTED-SIDQ FOR PATIENT WITHIN ONE WEEK OF ADMISSION

PATIENT WITHDRAWN AS PART OF EXCLUSION CRITERIA

PERSONAL CONSULTEE IDENTIFIED

PATIENT"S WISHES EXPLORED PRIOR TO LOSING CAPACITY/ NOT IN BESTINTERESTS TO PARTICIPATE

INFORMAL CARER

FORMAL CARER

PERSONAL CONSULTEE INFORMATION SHEET

INFORMAL CARER INFORMATION SHEET AND CONSENT FORM

FORMAL CARER INFORMATION SHEET AND CONSENT FORM

SUPPORT PATIENT INVOLVEMENT IN PROJECT

PERSONAL CONSULTEE DECLARATION FORM

ADMINISTER INFORMAL CARER ADAPTED-SIDQ WITHIN 1-2 WEEKS

ADMINISTER FORMAL CARER ADAPTED-SIDQ WITHIN 1-2 WEEKS

Figure 5Standard Operating Procedure for Consent Processes for recruitment for the Adapted Self-Identity in Dementia Questionnaire

3.8.1 Recruitment of individuals with dementia for the Adapted Self-Identity in Dementia Questionnaire

All patients admitted to the psychiatric in-patient assessment wards from July 2013 to July 2014 were screened for potential inclusion in the study. Patients were recruited from two wards within the acute hospital setting, Wards A and C (Ward A, n=14 and Ward C, n=1, as described in Section 3.7.1). The patient from Ward C was included as she was a recent admission to the ward and therefore met the criteria for the study.

Upon admission to hospital, nursing staff established if the patients met the inclusion criteria for the study. This was covered in the Registered Nurse consent processes. One individual with dementia did not meet these criteria as they were too physically unwell and awaiting transfer to the general hospital. During the period of the study, a total of 28 patients were admitted to Ward A and were considered for the study. Of these, 27 met the eligibility criteria; namely, a confirmed diagnosis of any type of dementia of any severity, be it mild, moderate or severe, medically stable, able to understand and speak English, and for whom consent might be reasonably obtained either through the individual or a Personal Consultee.

The mental capacity assessments, which consisted of the two-stage assessment, determined capacity to consent to participate in the study (Appendix 2). Those who were assessed to have capacity were able to sign the consent forms (n=18), but four of the informal carers declined and therefore, despite being willing to do so, were not able to continue participation in the study due to the multi-informant design required. From the original eighteen patients recruited, fourteen individuals with dementia were able to engage in the consent processes prior to participation.

Of these, a total of nine participants lacked capacity to consent to participate, with seven informal carers declining to progress further with the study, and two participants with dementia who had Personal Consultees who went through the process. Only one of these provided the information needed to determine if the individual would have liked to consent to participate prior to losing capacity (see Figure 6).

All patients with dementia were approached to take part in the study and the mental capacity assessment was used to determine capacity to consent to their inclusion. This was implemented using a conversational style to avoid undue pressure on the individual by the process being performed in a perfunctory and inaccessible manner. The written study information provided was shared by me and given specifically to those living with dementia.

I adopted this role due to the unknown factor in the recruitment process of how long recruitment and consent could take. The Registered Nurses would not have been able to spare this time from their nursing duties. I ensured plenty of time was given to the patients, whilst being available to answer any questions. It was an opportunity to clarify what was expected of them, what the purpose of completing the questionnaire was and what it would mean for them as a patient on the ward. It was explained to them that the questionnaire was being completed as part of a research project to see how useful the tool would be in measuring likes, dislikes and previous life roles. I explained what would be involved, including completing the questionnaire, how long it could take, and the support which would be available to them if needed, such as reading out questions or someone writing down what they wanted to answer. They were informed that their relatives would also be asked to answer similar questions, as well as their Named Nurse. The role

"Named Nurse" refers to the patient's key worker responsible for the co-ordination of all their nursing care and who usually looked after them when completing a similar questionnaire.

Depending upon the patient's level of cognitive or sensory impairment, this process took from only 20 minutes to over an hour, with an average of 30-40 minutes. A flexible approach was needed to accommodate the individual's needs, and if required I arranged to revisit the patient on another occasion.

Figure 6 shows the recruitment pathway, including the numbers of individuals with dementia who underwent the recruitment process.
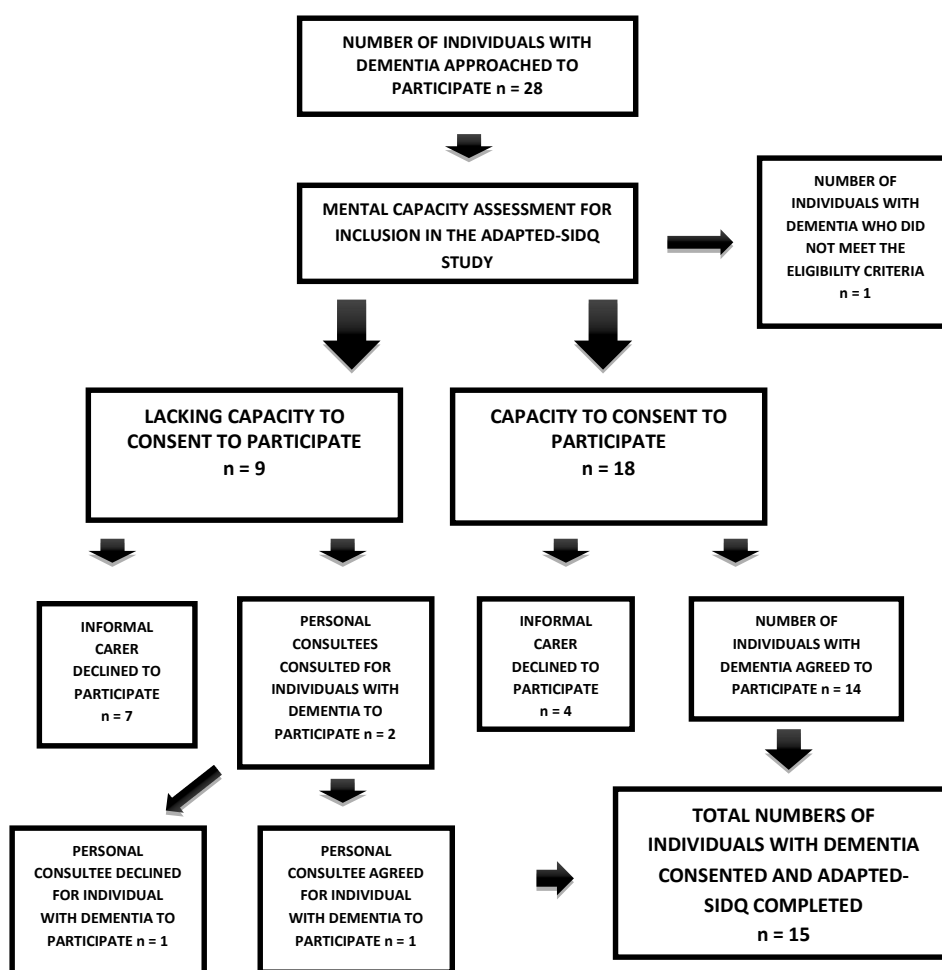
Figure 6Summary of recruitment and consent processes of individuals with dementia for the Adapted Self-Identity in Dementia Questionnaire

3.8.2 Participant characteristics of the individuals with dementia

In order to fully describe the characteristics of the persons with dementia, potential relevant relational factors were identified, and the following patient information was collected; gender and measures of cognitive and functional performance, diagnosis, source and reason for admission, and severity of mental illness and utilisation of the Mental Health Act (Department of Health, 1983, amended 2007). The Act provides a legal framework applied for those patients admitted to the study setting where voluntary admission is not forthcoming, but instead formal detention is permitted because it is deemed in the patient's best interest, to allow for assessment and treatment of mental illness. Under this legal framework, Section 2 of the Act permits an individual to be detained for up to 28 days, or under Section 3 of the Mental Health Act allows for detention for up to six months.

The Barthel Activities of Daily Living Scale is a validated scale used to measure performance in activities of daily living (ADL, developed by Mahoney and Barthel, 1965 and revised by Collin et al., 1988). The assessment tool measures functional performance and mobility, with points assigned to a level of ability. Total possible scores range from zero to 20, with lower scores indicating disability and higher scores indicating independence of function in certain tasks. These tasks include bathing and showering, dressing, abilities regarding personal hygiene, grooming, and toilet hygiene. This tool is part of the ward assessment process when individuals are admitted to the in-patient ward, to determine their abilities regarding self-care.

This particular tool was chosen as it is a validated tool, already embedded as part of the assessment process, all members of the multidisciplinary team are aware of its indications related to dependency level, and targeted interventions can be implemented to enhance abilities to promote independence. Although a popular tool, Bowling (2005) claims that due to the negative focus on disability and not ability, it does not truly represent the patient's abilities, as well as being open to subjective assessments which may impact on inconsistencies in scoring.

For the purpose of determining an individual's level of cognitive ability in this study, the Mini Mental State Examination or MMSE (Folstein et al., 1975) was used. Other cognitive assessment tools are available such as the Addenbrooke's Cognitive Examination (Mioshi, Dawson, Mitchell, Arnold and Hodges, 2006) and Montreal Cognitive Assessment (MOCA), which are used in the diagnosis of cognitive impairment. The MMSE (Folstein et al., 1975) is widely used in clinical practice as a "bed side" assessment as it is quick and easy to implement, can be used to measure deterioration in cognition over a period of time, and is a routine assessment on admission to Ward A. It is a well-validated tool being used within health and social care, as well as research into dementia. The assessment focuses on five areas of cognition; orientation, registration, attention, recall and language. With a total score of 30, any score greater than 27 indicates "normal" cognition, whilst 19-24 indicates mild impairment, 10-18 moderate cognitive impairment, and scores below 9indicate severe cognitive impairment.

According to Bowling (2005) the MMSE has good inter-rater and test-retest reliability, and is preferable to other tests such as the Abbreviated Mental Test Score (AMTS), but it can be biased towards those with lower educational attainment, or those with visual impairments whereby scores need to be adjusted. Table 9 summarises the demographic profile and presentation characteristics of the study participants with dementia.

Table 9 Participant characteristics from the individuals with dementia included in the study

TOTAL NUMBER OF INDIVIDUALS WITH DEMENTIA (n = 15)

Baseline Characteristics for individuals with dementia	Sub-type	Number (n)	Percentage (%)
Gender	Female	7	46%
	Male	8	54%
Education	Completed part of Elementary school	1	7%
	Completed Elementary school	6	40%
	Completed part of Secondary school	7	46%
	Bachelors' Degree	1	7%
Diagnosis	Alzheimer's Disease (AD)	8	53%
	Vascular dementia (VaD)	3	20%
	Mixed diagnosis (AD and VaD)	4	27%
Mental Health Act status	Informal	3	20%
	Section 2 MHA	8	54%
	Section 3 MHA	4	26%
Source of admission	Own home	9	60%
	Residential/Nursing home	5	33%
	General hospital	1	7%
Reasons for admission	Severe BPSD	6	40%
	Risk to self	5	34%
	Delirium	2	13%
	Crisis of care provision	2	13%
Mini Mental State Exam (MMSE) Total score possible = 30 with lower scores indicating more severe impairment	Mean (Range)	14.8 (4 - 24)	
	Mild cognitive impairment (24-30)	4	
	Moderate cognitive impairment (18-23)	8	
	Severe cognitive impairment (0-17)	3	
	Standard Deviation	6.0	
Barthel Activities of Daily Living (ADLs) Total score possible = 20 with lower scores indicating disability.	Mean (Range)	11.3 (4 - 18)	
	Low functional impairment (15+)	4	
	Moderate functional impairment (11-14)	4	
	High functional impairment (10 or less)	7	
	Standard Deviation	5.1	

Cognitive impairment: There were 15 participants with a confirmed diagnosis of dementia, with almost an equal gender balance (eight males to seven females). More than half of the participants with dementia had a diagnosis of Alzheimer's disease (53%), with the remainder divided between Vascular Dementia (20%) and mixed dementia (27%). The study participants had a range of MMSE scores from four (severe impairment) to 24 (mild cognitive impairment) out of a total score of 30. Four participants had scores in the 18-23 category indicating a mild impairment, but the majority of patients were assessed to be in the moderate impairment group (8/15), and three individuals had a score of a MMSE of 17 or less, indicating a severe impairment.

Functional ability: This was measured using the Barthel Activities of Daily Living (ADL, Collin et al., 1988) score, with a range of scores from four (lower scores representing increased disability) to 18 (independent) out of 20. The range of Barthel ADL scores reflects both the functional and cognitive abilities of the participants regarding self-care activities. There were four patients with Barthel ADL scores of 15 or more, four patients scored 11-14, and the majority (7/15) scored 10 or less, indicating a higher level of dependency based upon levels of functioning at the time of assessment.

Educational attainment: This was measured to provide insight to the highest levels of education that the participants achieved, and the impact it may have had on job, profession or occupational role, hobbies and interests in later life. Almost half of the participant's ceased full-time education between the ages of 14-16 years, with half going onto secondary education (7/15), and one participant held a Bachelors' Degree. This was part of the original SIQ and had not been removed from the questionnaire in its redesign.

Source of admission: The majority of participants were admitted to the acute psychiatric assessment ward from their own home, while a third originated from local residential or nursing homes. There was only one patient as an exception, who was transferred from the local general hospital for ongoing assessment of their mental health needs.

Of these, just over half (8/15) required formal detention and admission to the acute psychiatric in-patient unit under Section 2 of the Mental Health Act, a third (4/15) were admitted under Section 3 of the Mental Health Act, and three patients were admitted informally. At the time of the study no patient was deemed Deprived of their Liberty (DoLs) under the Mental Capacity Act (Department of Health, 2005).

Reasons for admission to the study setting: As documented in the patient electronic health record, reasons given for admission to the acute psychiatric in-patient ward included behavioural and psychological symptoms associated with dementia, known as "BPSD" (n=6), and severe risk to self or others (n=5). Examples of behavioural disturbance included "*wandering the streets and found by police in a disorientated and confused manner*", "*attempted to abscond from the residential home on three occasions*" and "*severe self-neglect, non-adherence to medications and not eating and drinking*". Examples of documented risks to others included "*increased resistance to personal care with increased aggression towards staff and other residents*", "*aggressive towards carers, resisting care and refusing medications*", and "*aggression and severe violence towards family*". Ongoing delirium exacerbating dementia symptoms was documented for two patients, whose dementia symptoms had deteriorated due to underlying physical health needs. Crisis of care provision was the reason for two patients being admitted; one where a patient's wife was admitted to the general hospital following a stroke and

he was unable to care for himself, and the second patient was unable to be supported at home with community carers.

In summary, the participants were not a homogenous group, but represented a range of participant characteristics. There was an equal gender balance, but different dementia diagnoses which represented the most commonly diagnosed types of the illness. The ranges of severity of dementia were mostly mild to moderate, but participants included three with severe cognitive impairment, and functional ability was determined as predominantly moving from independent to dependent. There were several admission routes and reasons for admissions with detentions under different requirements of The Mental Health Act (Department of Health, 1983).

3.8.3 Recruitment of informal carers for the Adapted Self-Identity in Dementia Questionnaire

Informal carers were approached by either me or a Registered Nurse to enquire whether they would be interested to take part in the study. During initial conversations, the purpose of the study was outlined including what would be involved in contributing for both the individual with dementia and their informal carer. Reassurances were provided regarding the minimal risks of participation for them or the individual with dementia, such as no risk of physical injury, and the measures put in place to reduce the risk for potential psychological or emotional distress. For those who were interested, the recruitment pack was handed to them in a sealed envelope. They were asked to consider their participation and read the material provided about the study. If they had any further questions they were advised to ask me or the nursing staff for clarification. Lastly, they were asked to return the completed consent form and questionnaire to the Ward A office

depending upon their decision to participate or not. Fifteen informal carers met the eligibility criteria for the study as follows; that the individual with dementia was participating and that they, as their informal carer, had known the individual with dementia for a minimum of five years to be able to answer questions posed in the Adapted-SIDQ. Five informal carer participants were husband or wife to the patient, eight were the son or daughter of the individual with dementia and two siblings were informal carers who participated. Figure 7 summarises the recruitment and consent processes for the informal carer participant group.
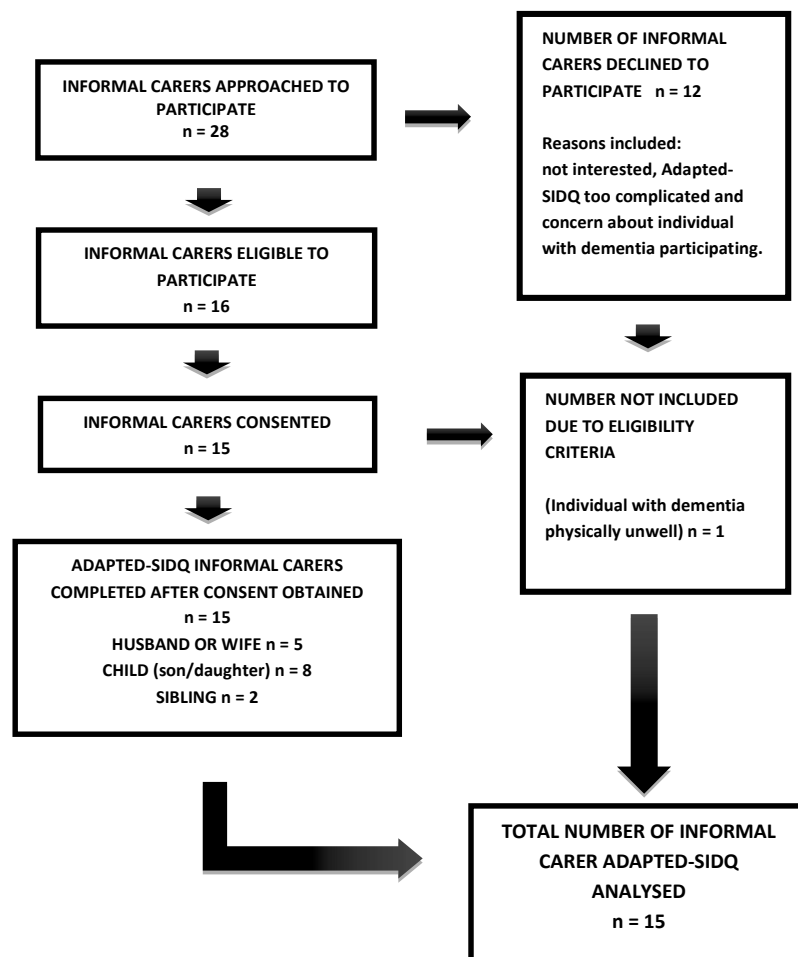
Figure 7 Summary of recruitment and consent processes for informal carers for the Adapted Self-Identity in Dementia Questionnaire

<u>Non-participation of informal carers:</u>

Of the 28 informal carers approached and eligible to take part, a total of 12 subsequently decided not to take part in the study. If the informal carer declined to take part, they were free to do so without giving a reason for non-participation. Further questioning regarding the rationale for not partaking was not pursued to comply with ethical approval conditions. Where the reason for non-participation by an informal carer was volunteered, it was documented. Explanations provided were a lack of interest, not wanting the individual with dementia included in the study due to perceived harm it may induce, and a feeling that the questionnaire was "*too complicated".*

Following consent processes, one informal carer was withdrawn from the study as their relative with dementia became physically unwell, and was therefore unable to participate as they no longer met the eligibility criteria as the total data set for this participant group could not be obtained. Overall a total of fifteen informal carers consented to participate in the study.

3.8.4 Recruitment of Registered Nurses as formal carers for the Adapted Self-Identity in Dementia Questionnaire

Six Registered Nurses from Ward A met the study eligibility criteria, in that they were Registered Nurses with the Nursing and Midwifery Council (NMC), and were designated as "Named Nurse" for one or more individuals with dementia taking part in the study. From a total of 11 nurses working across the two wards (Wards A and C), six participated in the study. The Registered Nurses worked across both Ward A and Ward C, and knew all the patients. Two nurses worked permanent night shifts and were unable contribute as the majority of study activity needed to

be completed within day shift hours. Their exclusion from the study was considered after discussion with them, and the issue had not previously been considered an exclusion criteria. Two nurses were newly Registered Nurses under preceptorship and therefore were now practicing autonomously, and one nurse was absent through sickness reasons.

Following an educational session on the research study, the informed consent process for the six Registered Nurses was explained. They were given the information leaflet which included full details of the study, and a recruitment letter. There was an opportunity to ask questions related to the study, including what their role was in completing the Adapted-SIDQ and how to access support should they need it.

All Registered Nurses who participated signed the formal carer written consent form prior to their involvement. Figure 8 summarises the recruitment and consent processes for the formal carer participant group, and indicates the number of Adapted-SIDQ questionnaires completed for each of the nurses taking part in the study. If a Registered Nurse had more than one patient on their caseload, for each patient taking part in the study, under their care as Named Nurse a separate corresponding questionnaire was completed.

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┌─────────────────────────────────────────────┐
│   FORMAL CARERS ELIGIBLE TO PARTICIPATE n = 6 │
│        4 Registered Mental Health Nurses      │
│           2 Registered General Nurses         │
└─────────────────────────────────────────────┘
                      ▼
┌─────────────────────────────────────────────┐
│         FORMAL CARERS CONSENTED n = 6         │
└─────────────────────────────────────────────┘
                      ▼
┌─────────────────────────────────────────────┐
│  6 Registered Nurse Formal Carers completed   │
│            the Adapted-SIDQ;                   │
│                                               │
│  Registered Nurse x1 completed five           │
│            Adapted-SIDQs                       │
│                                               │
│  Registered Nurse x 1 completed three         │
│            Adapted-SIDQs                       │
│                                               │
│  Registered Nurses x 3 completed two          │
│            Adapted-SIDQs                       │
│                                               │
│  Registered Nurse x1 completed one            │
│            Adapted-SIDQ                        │
└─────────────────────────────────────────────┘
                      ▼
┌─────────────────────────────────────────────┐
│     TOTAL NUMBER OF FORMAL CARERS             │
│      ADAPTED-SIDQ ANALYSED n = 15             │
└─────────────────────────────────────────────┘
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Figure 8Summary of recruitment and consent processes for formal carers for the Adapted Self-Identity in Dementia Questionnaire

In summary, six Registered Nurses consented to participate in the study; the majority of whom were Registered Mental Health Nurses (n=4), with two Registered General Nurses also taking part. All nurses had a minimum of three years' experience post-registration within their chosen speciality of nursing, and a minimum of two years working with people with dementia on either Ward A or C. All nurses also worked full time and were required to work across 24 hour shift patterns, but as the ward had Registered Nurses who worked permanent night shifts, those who predominantly worked the day shifts and performed the Named

Nurse role with the patients were involved in the research study. Five Registered Nurses were unable to participate due to working shift patterns, preceptorship or absence due to sickness.

3.9 Study data collection methods for the Adapted Self-Identity in Dementia Questionnaire

The Adapted-SIDQ had several modes of administration throughout the study. For the individuals with dementia (depending upon their specific cognitive needs) some were able to read and complete the questionnaire independently, whereas others were able to do so with minimal support and guidance only. However, other individuals needed one-to-one support to go through each question, whilst I provided cues and prompt throughout to obtain responses. This flexible approach ensured that the process was individualised to each participant's specific communication, language and cognitive abilities. I facilitated the completion of the Adapted-SIDQ for those with dementia, and ensured the data was collected as required.

The informal carer Adapted-SIDQ was either hand delivered by myself or by Ward A or C nursing staff. Once the questionnaires were completed for the individuals with dementia and their informal carers, the Registered Nurses as formal carers completed their Adapted-SIDQ which was either hand delivered or posted via their personal mail tray on Ward A or C. Once completed, the questionnaires for the informal and formal carers were delivered back to me by hand in a sealed envelope provided with the questionnaire or through my mail tray in the envelope, and secured in a locked cupboard as per ethical governance.

3.10 Data handling and analysis for the Adapted Self-Identity in Dementia Questionnaire

The feasibility study aimed to use a systematic approach to validating the Adapted-SIDQ as an effective research tool. The Adapted-SIDQ yielded both quantitative results and additional qualitative data from the free text questions.

3.10.1 Quantitative analysis

As the research was a feasibility study, all analyses were treated as preliminary and exploratory, and were predominantly descriptive.

Statistical Package for the Social Sciences (SPSS) - SPSS is an integrated quantitative analysis software package, widely used within social sciences (Acton, Miller, Maltby and Fullerton, 2009). It was chosen due to its efficiency and capability in handling data, its multifunctional abilities in data analyses as required for this research study, and the fact I was familiar with the software. IBM SPSS Statistics 22 and 24 versions were used, and analysis commenced throughout data collection from July 2013 until September 2014.

Descriptive statistics - Descriptive statistics were used to describe features of the quantitative data collected from the Adapted-SIDQ such as percentages, means and ranges. Tabulated and graphical depiction provides information and summarised results related to the self-identity roles of those with dementia and the importance of these roles, whilst also summarising details from the self-identity dimensions of the Adapted-SIDQ.

<u>Cohen's kappa (κ) coefficient and weighted kappa</u> - Cohen's kappa (κ) is a measure of inter-rater agreement for categorical scales when there are two or more raters. Cohen's kappa (κ) can range from -1 to +1. The Kappa (*κ*) statistic is a quality measure that compares observed agreement between two raters on a nominal or ordinal scale with agreement expected by chance alone. In the case of ordinal data, a weighted kappa is used, which reads as usual kappa with off-diagonal elements contributing to the measure of agreement.

In the original Cohen-Mansfield et al. paper (2000) no specific method for statistical nor correlation analyses was included. It states "statistical analysis" (p.385), "the agreement rate between staff and relatives" (p.390) and "correlations between staff and family perceptions" (p.390). Therefore it was a challenge to determine from the published paper how the levels of agreement in Cohen Mansfield et al.'s paper (2000) were calculated.

Rationale for the use of a weighted kappa for data analysis included;

1. Cohen's (1960) kappa is the most used summary measure for evaluating inter-rater reliability. According to the Social Sciences Citation Index (SSCI), Cohen's (1960) seminal paper on kappa is cited in over 3,300 articles between 1994 and 2009 (Zhao, 2011).

2. The literature has identified that a weighted Cohen's kappa coefficient has been used within mental health and psychosocial based research studies (Lamers et al., 2008, [depression screening in chronically ill older adults], Sheehan et al., 1998 [development of a mini international neuropsychiatric interview] and Tang et al., 2015 [depression in primary care]).

3. It is thought to be a more robust measure than simple percent agreement calculation, since the weighted kappa takes into account the possibility of the agreement occurring by chance.

4. A weighted Kappa statistic is easily calculated and software is readily available through SPSS.

5. To determine the inter-rater agreement between individuals living with dementia and both their informal and formal carers to provide a quantitative measure of the magnitude of agreement.

6. Weighted kappa coefficients are commonly used to quantify agreement between two raters on K-ordinal scales. The data generated from the Adapted-SIDQ would be on an ordinal scale (levels of importance ranging from not at all important, slightly important, moderately important, important and very important and agreement on attitudes towards self-identity domains). A weighted kappa coefficient is computed that takes into consideration the different levels of disagreement between categories. For example, if one rater 'strongly disagrees' and another 'strongly agrees' this must be considered a greater level of disagreement than when one rater 'agrees' and another 'strongly agrees'.

As the data collected was preliminary and exploratory, consideration had been given to using simple percentage agreements, but discussions on accuracy and precision related to the levels of agreement between participants was deemed too important to not explore statistically. Therefore the weighted Kappa co-efficient was deemed the most appropriate measure for this study.

Based on the guidelines from Altman (1999), and adapted from Landis and Koch (1977), kappa (κ) values of < 0.20 are considered as only a slight agreement, 0.21 - 0.40 is fair, 0.41 - 0.60 is moderate, 0.61 - 0.80 is substantial and 0.81 or above is considered an almost perfect level of agreement. However, according to Altman (1999) any level of agreement above 0.70 is conventionally considered to be adequate (Table 10).

Table 10 Interpretation of a weighted Cohen's kappa (κ) coefficient, adapted from Altman (1999)

	Poor	Slight	Fair	Moderate	Substantial	Almost Perfect
	0.0	0.20	0.21-0.40	0.41-0.60	0.61-0.80	0.81-1.00

Weighted Kappa score	Level of Agreement
<0	Less than chance agreement
0.01 – 0.20	Slight agreement
0.21 – 0.40	Fair agreement
0.41 – 0.60	Moderate Agreement
0.61 – 0.80	Substantial agreement
0.81 – 1.0	Almost perfect agreement

The weighted Cohen's (κ) coefficient was calculated to determine if there was agreement between the individual with dementia, the informal carer and formal carer, and between the past and present. The relative importance placed by each of the groups was to be explored with regards to aspects of self-identity (job,

occupational and professional role, family roles, hobbies and activities and personal achievements, attributes and traits).

Data was coded and entered into SPSS. All the data sets were complete, with no element of the multi-informant Adapted-SIDQ missing. SPSS generated two main tables of output for the weighted Cohen's kappa; the cross tabulation table to understand the degree to which the raters (individual with dementia, informal carer or formal carer) agreed or disagreed on their judgement of the level of importance of each self-identity role, and symmetric measures tables which provided the kappa value for levels of importance.

3.10.2 Additional data analysis

The Adapted-SIDQ produced additional data from the open-ended questions related to self-identity, such as "*In which ways could we, in your opinion enhance or cultivate the self-identity feelings of the participant?*" This was analysed to establish if there were similarities between the participants, and due to the individualised nature of the data, it was fed back to the Registered Nurses in coordinating the individual with dementia's care for the benefit of additional knowledge pertinent for person centred care planning whilst an in-patient on the ward.

3.11 Chapter Three Summary

Chapter Three has introduced both Phase One and Two of the research study. Phase One described aspects of this feasibility study, as well as the consultation, adaptation and co-design of the SIDQ, including stakeholder involvement

representing the three participant groups. Details of the synthesis of feedback were provided and subsequent development of the Adapted-SIDQ was made.

Prior to its implementation, specific ethical considerations were highlighted, including the application of the Mental Capacity Act (Department of Health, 2005) to research activities involving those with dementia.

Phase Two outlined the study setting, inclusion and exclusion criteria, recruitment of the participant groups and the processes involved in the implementation of the questionnaire within the clinical setting, summarising data collection, data handling and analysis using a weighted kappa for statistical analysis.

Chapter Four will now present the analysis and findings from the Adapted-SIDQ.

Chapter Four - RESULTS FROM IMPLEMENTING THE ADAPTED SELF-IDENTITY IN DEMENTIA QUESTIONNAIRE

In this chapter the analysis and findings will be presented from the Adapted Self-Identity in Dementia Questionnaire (Adapted-SIDQ).

4.1 Research questions:

To determine whether an adapted version of the Self-Identity in Dementia Questionnaire was feasible in ascertaining dimensions of self-identity within an acute psychiatric assessment ward, the following questions were posed:

(i) To what extent can dimensions of self-identity in individuals with dementia be ascertained when admitted to an acute psychiatric hospital for older adults using a culturally Adapted Self-Identity in Dementia Questionnaire?

(ii) Is the culturally Adapted Self-Identity in Dementia Questionnaire an acceptable, practical and appropriate tool for use within the clinical assessment and care of individuals living with dementia?

The Self-Identity in Dementia Questionnaire (SIDQ) was adapted to a suitable format for a United Kingdom population, including its different culture, care group and care setting.

Using an adapted version of the Self-Identity in Dementia Questionnaire can the following be answered?

(i)   What are the self-identity roles that individuals with dementia identify with?

(ii)   What is the strength of these self-identity roles?

(iii)   What is the extent of agreement between the individuals with dementia, informal carers and formal carers about the sense of identity?

(iv)   What, if any, are the ways that different informants think self-identity information can be elicited?

(v)   What, if any, are the ways that different informants perceive self-identity can be enhanced and what is the potential impact of this?

Using a weighted Cohen's kappa coefficient, the levels and extent of agreement between the three participants groups related to the different aspects of identity will be described and summarised. The chapter will highlight the ways that self-identity can be elicited from individuals with dementia, reviewing the results from the individual's choice of name, and the behaviours and conversation topics they engage with. Finally, the methods by which self-identity can be enhanced and the potential impact of this will be provided, with additional data on personality and identity change from the perspective of informal and formal carers.

The Adapted Self-Identity in Dementia Questionnaires can be seen in Appendices 3; for the individual with dementia, Appendix 3 (i), for the informal carers, Appendix 3 (ii), and for the formal carers, Appendix 3 (iii).

4.2 The roles individuals with dementia identify with and comparisons between past and present importance levels, including the relative strength of these roles

In order to answer the question 'What are the self-identity roles that individuals with dementia identify with?', the results from each of the four self-identity domains (job, occupational or professional role, family role, hobbies and activities, and

personal attributes, achievements and traits) will be presented. The strength of these roles according to the individuals living with dementia, their informal carers and formal carers and their level of importance will also be presented.

4.2.1 Job, occupational or professional role

The question posed for the individuals with dementia in the Adapted-SIDQ (Appendix 3, Section A, Q1) was '*What was your main job, occupation or profession*?'
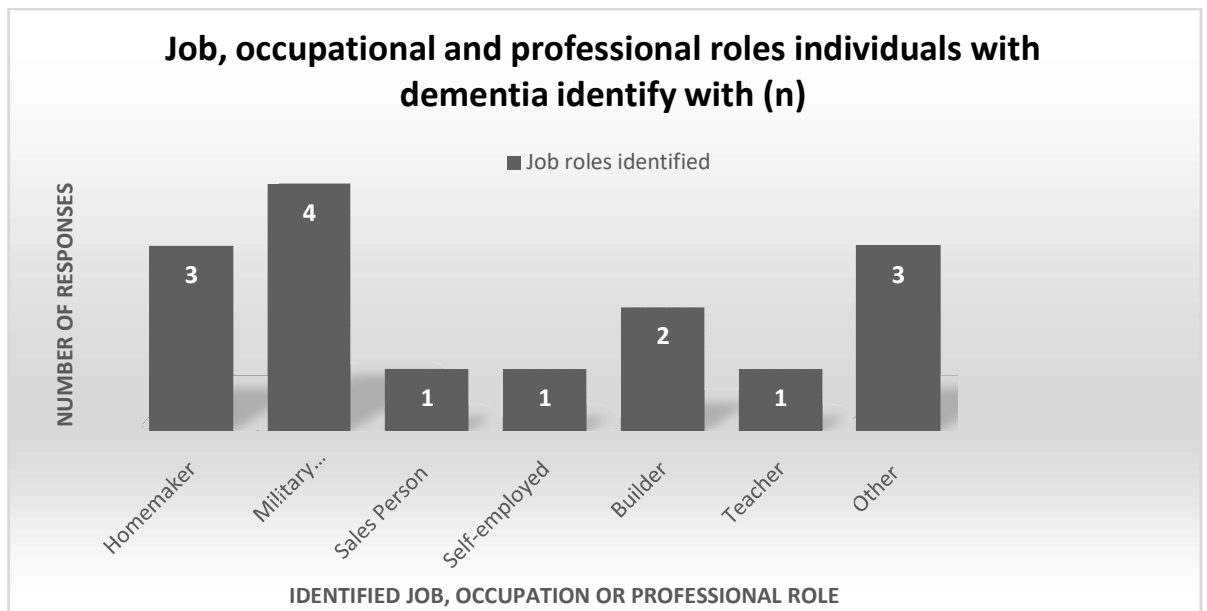
Figure 9 Job, occupational and professional roles individuals with dementia identified with

When asked about their job, occupation or profession, individuals with dementia reported the most frequently identified job role was those that worked as military personnel (n=4), followed by home maker (n=3) and small proportions were identified under the categories of sales persons, builder and teacher. Three individuals reported job roles under the 'other' category. The three occupations not listed were described as; (i) '*working in the Dockyard'*, (ii) '*working in a lab*' and (iii) '*electrician*'. All participants with dementia described themselves as having been employed or having worked throughout their lives in some capacity, but it

was not clear whether this was full-time or part-time work, or continuous employment.

Importance of job, occupational and professional roles in the past and present for individuals with dementia (n)
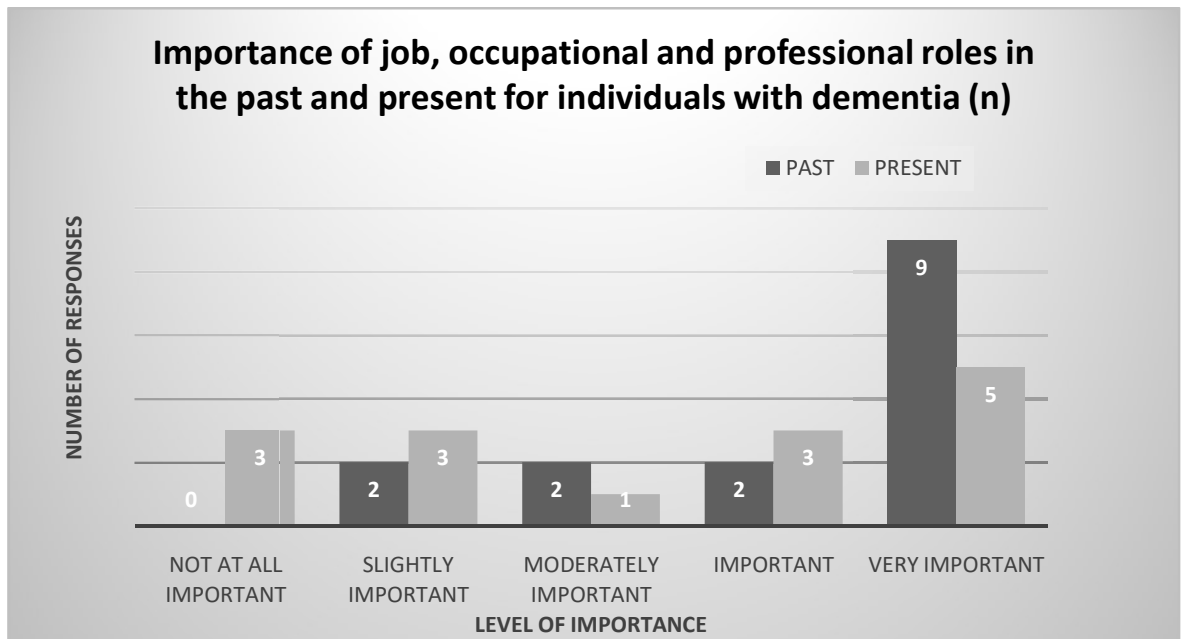
Figure 10 Levels of importance of job, occupational and professional roles in the past and present for individuals with dementia

The Adapted-SIDQ asked *'How important is this job, occupation or profession to you today*?' (Section A, Q2) and *'How important was this job/occupation to you in the past?'* (Section A, Q3).

All the patients included in the study had retired and were no longer in employment.

Figure 10 demonstrates the differences between the levels of importance of job role in the past and present. This group felt predominantly that their previous occupational roles were 'very important' to them in the past, (n=9). No participants felt that their job role was 'not at all important' in the past. In the present, the individuals with dementia changed their position on how important their job, occupational or professional role was from their thoughts on its importance in the

past. Five participants with dementia stated it remained 'very important' today, compared to nine participants who had previously reported it had played a 'very important' role in the past. The level of importance was reduced to 'not at all important' for three individuals with dementia, or to 'slightly important' (n=3). This indicated that job role; its importance in the present and its impact on self-identity was inconsistent from this sample.

4.2.2 Family relationship roles

The question posed from the Adapted-SIDQ for the individual with dementia (Section B, Q6) was '*Which family relationship was most important for you*?'
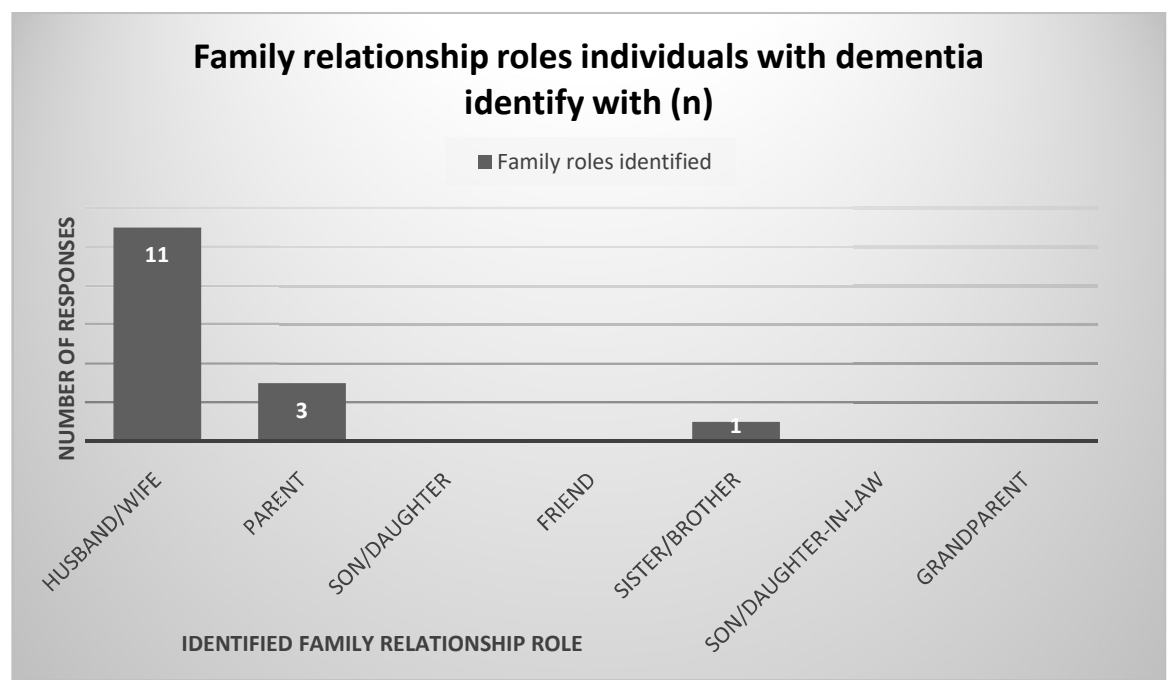
Figure 11 Family roles that those with dementia identified with

The majority of individuals with dementia (n=11) reported that the family relationship most important to them was that of being a husband or wife, followed by being a parent to children (n=3), and one participant felt being a sibling was the most important relationship.
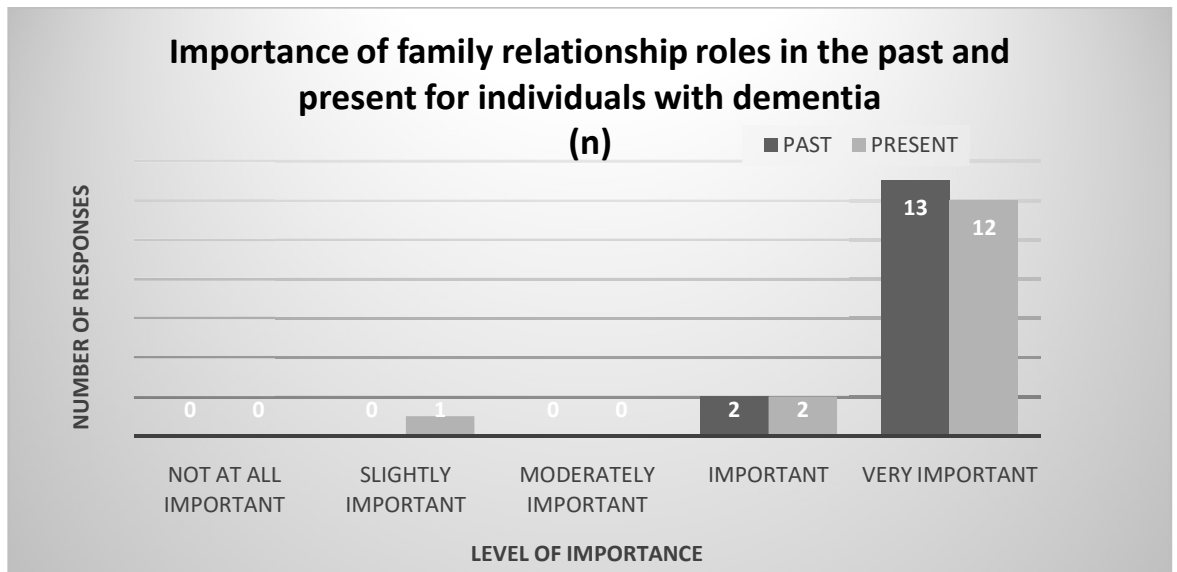
Figure 12 The importance of family roles in the past and present for individuals with dementia

The Adapted-SIDQ asked the individuals with dementia '*How important was this relationship [mentioned in Q1] to you in the past*?' (Section B, Q8).

For the individuals with dementia the relationships identified were predominantly 'very important' in both the past and the present, indicating that husband and wife were the most important roles in both time frames. Responses also included 'important' (n=2) and 'slightly important' (n=1). In the present there was very little change in individual's preferences across the group, although one participant changed their thoughts on level of importance from the past to the present, with their significant relationship changing from 'very important' to only 'important', but the reasons for this change were unknown.

4.2.3 Hobbies and Activities

Three questions posed in the Adapted-SIDQ for the participants were about hobbies and activities (Section C, Q1-3); *Q1 'What are some of your favourite things to do (other than work)?' Q2 'How important were these hobbies and*

activities to you in the past?' and *Q3 'How important are these hobbies and activities to you today?'*

Participants chose more than one category from the list of hobbies and activities provided in the Adapted-SIDQ reflecting their favourite hobbies and activities to engage in, with no limit on the amount of choices they could make.
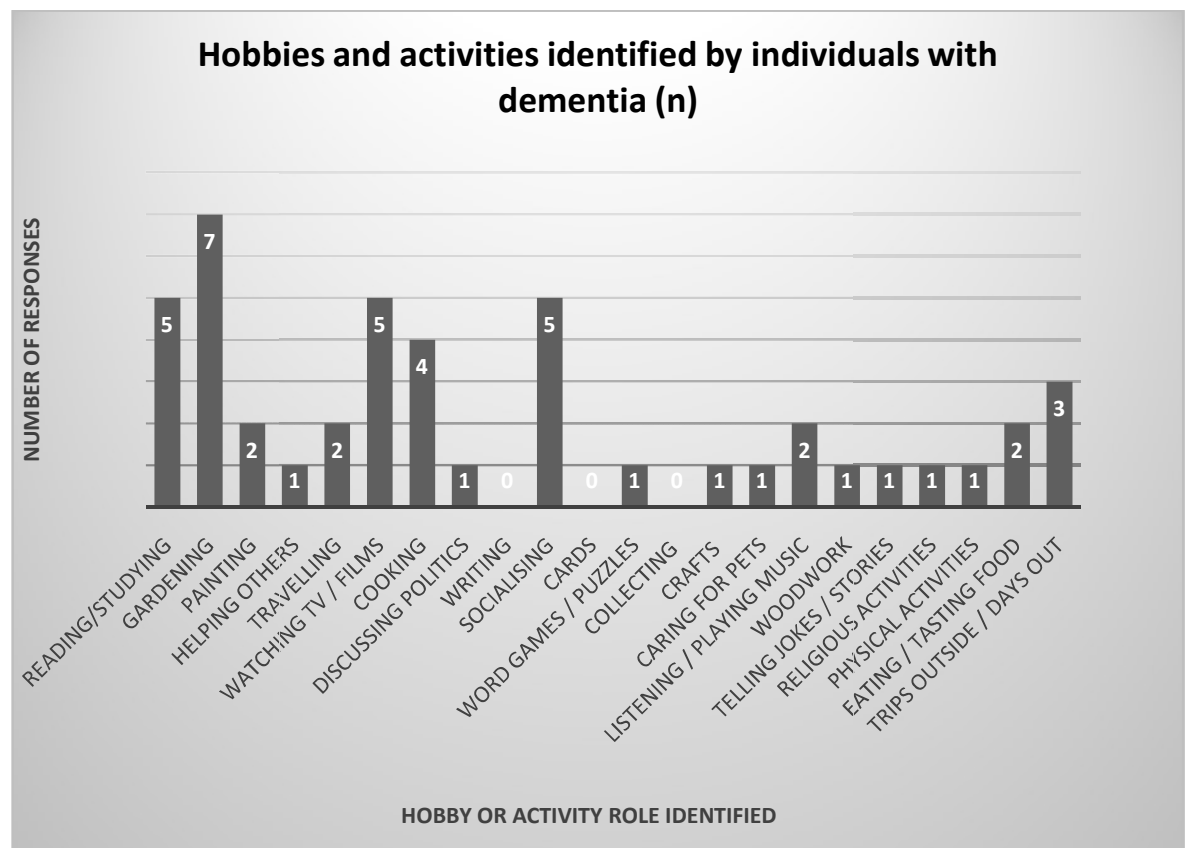
Figure 13 Hobbies and activity preferences as identified by individuals with dementia

Overall there were 55 different responses chosen by the 15 individuals with dementia. The most popular hobby or activity was gardening (n=7), followed by reading or studying, watching television or films, and socialising. Trips out was important to three individuals with dementia. The least popular activities for this cohort included religious activities, caring for pets and word games.
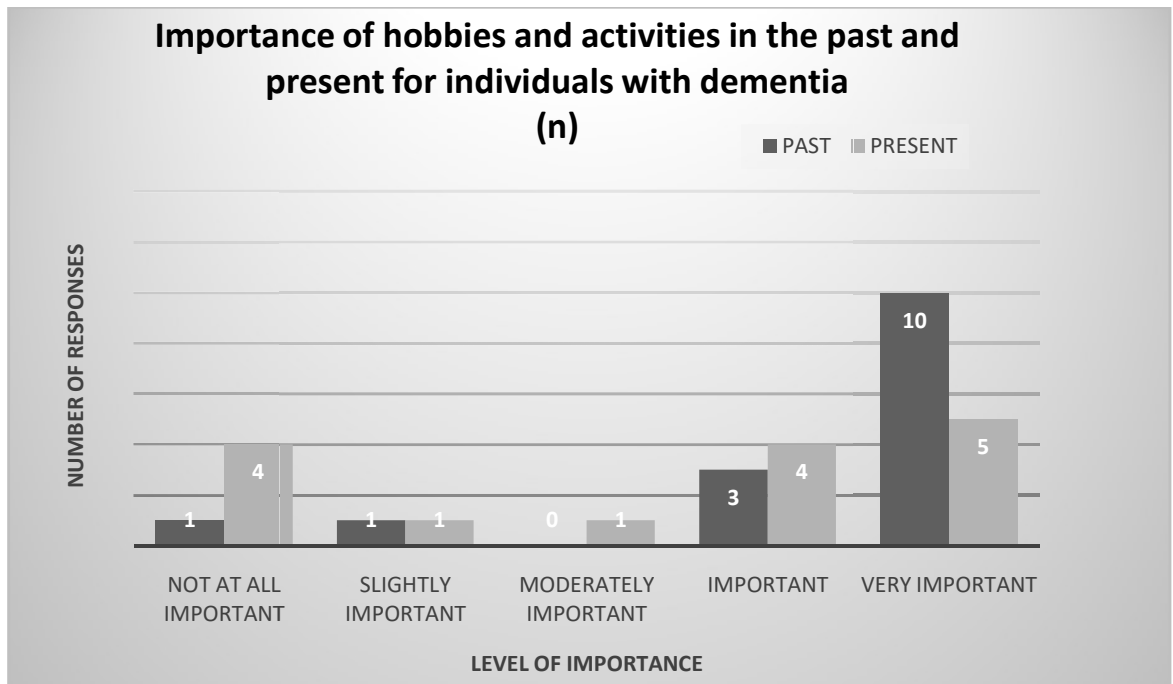
Figure 14 The importance of hobbies and activities in the past and present for individuals with dementia

In the past, hobbies and activities were 'very important' for the individuals with dementia (n=10), with only one participant responding 'not at all important' and another for 'slightly important'. The results from this group varied across the available responses, with five participants stating their hobbies and activities in the present are 'very important', yet similarly four individuals with dementia felt that they were 'not at all important'.

4.2.4 Personal achievements, attributes or traits

The questions posed from the Adapted-SIDQ were based around personal achievements, attributes or traits (Section D, Q1-3); Q1 *'In which things are you especially proud?'* Q2 *'How important were these achievements, attributes and traits to you in the past?'* and Q3 *'How important are these achievements, attributes and traits to you today?'*

Participants chose more than one category from the list of personal achievements, attributes or traits provided in the Adapted-SID reflecting what they identified with.
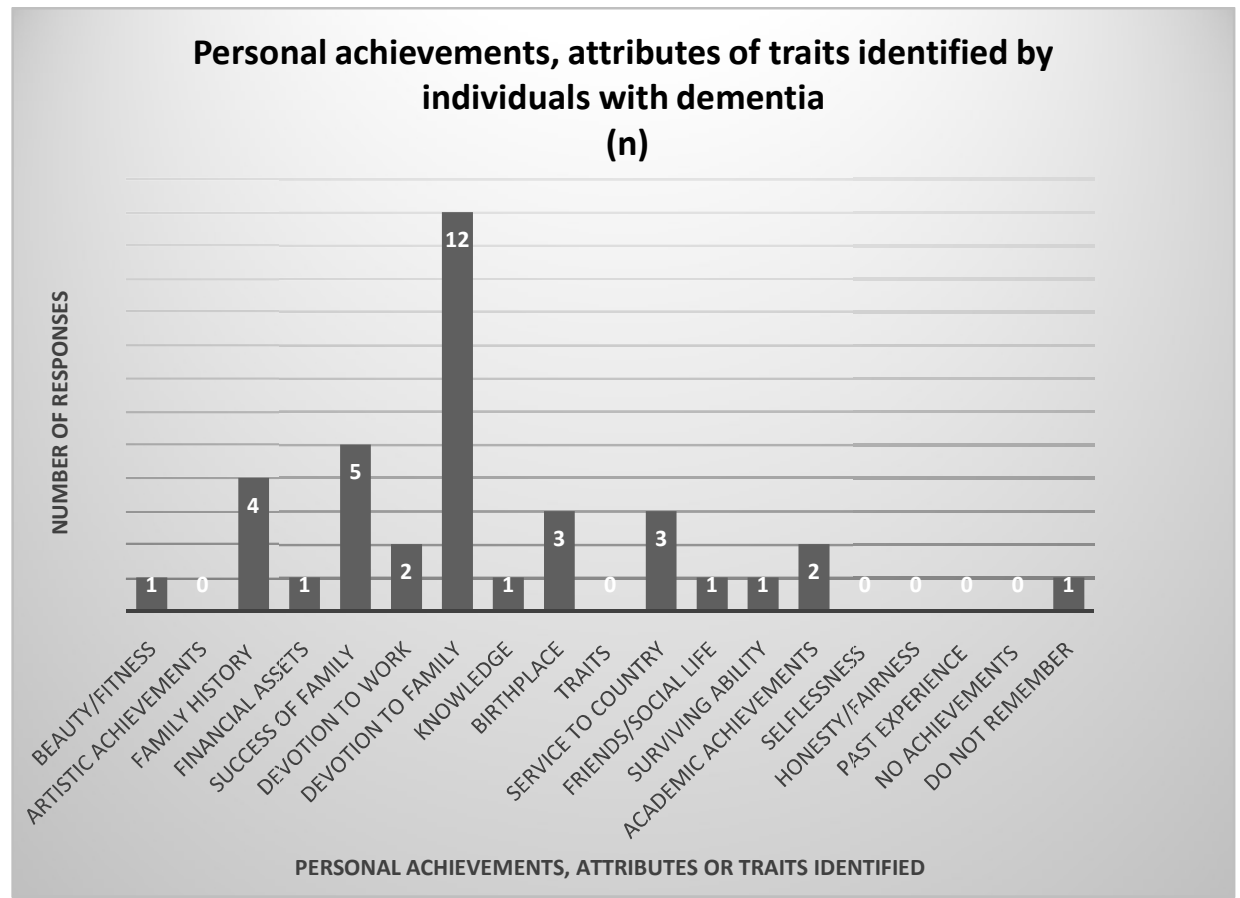
Figure 15 Personal achievements, attributes and traits as identified by individuals with dementia

For the individuals with dementia, significant personal achievements, attributes or traits that people identified as important included devotion to family (n=12), success of a family member (n=5), family history (n=4) and birthplace (n=3), as well as service to country being particularly important for three participants.
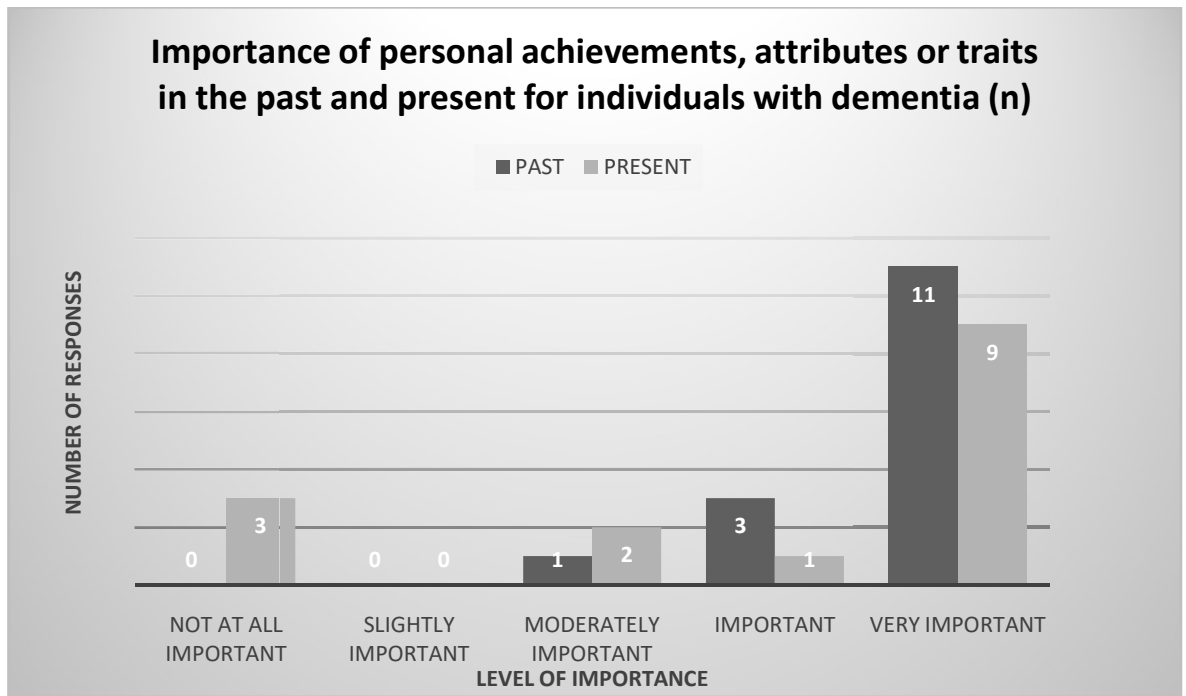
Figure 16 The importance of personal achievements, attributes or traits in the past and present for

individuals with dementia

In the past, the levels of importance of achievement, attributes and traits had been 'very important' for 11 out of 15 individuals with dementia. It remained 'very important' to nine participants in the present, but three felt that the level of importance had changed and was now 'not at all important'.

4.3 The extent of agreement between the individuals with dementia, informal carers and formal carers about the sense of identity for those with dementia

In order to answer the question *'What is the extent of agreement between the individuals with dementia, informal carers and formal carers about the sense of identity?'*, the results from each of the four self-identity domains (job, occupation or professional role, family role, hobbies and activities, and personal attributes, achievements and traits) will be presented.

As the research was a feasibility study, all analyses were treated as preliminary and exploratory, and were predominantly descriptive. However, to determine the extent of agreement between the individuals with dementia, informal carer and formal carers about the sense of identity, Cohen's weighted kappa coefficient was used, which is a measure of inter-rater agreement for categorical (ordinal) scales when there are two or more participants. A weighted Cohen's kappa (κ) can range from -1 to +1. Based on the guidelines from Altman (1999), and adapted from Landis and Koch (1977), kappa (κ) values of <0.20 are considered a slight agreement, 0.21-0.40 fair, 0.41-0.60 moderate, 0.61-0.80substantial and 0.81-1.00 is considered an almost perfect level of agreement. It was used to calculate the levels of agreement not only between the past and present, but also between participant groups. Analysis was conducted on levels of importance relating to each identity role, and attitudes towards those identity roles from the perspective of informal and formal carers.

4.2.1 Job, occupational or professional role

The Adapted-SIDQ asked *'How important was this job/occupation to you/your relative in the past?'* (Section A, individuals with dementia Q3, and informal carer Q5). Formal carers were not included in this question as they would not have prior knowledge related to the individuals with dementia's previous job roles.
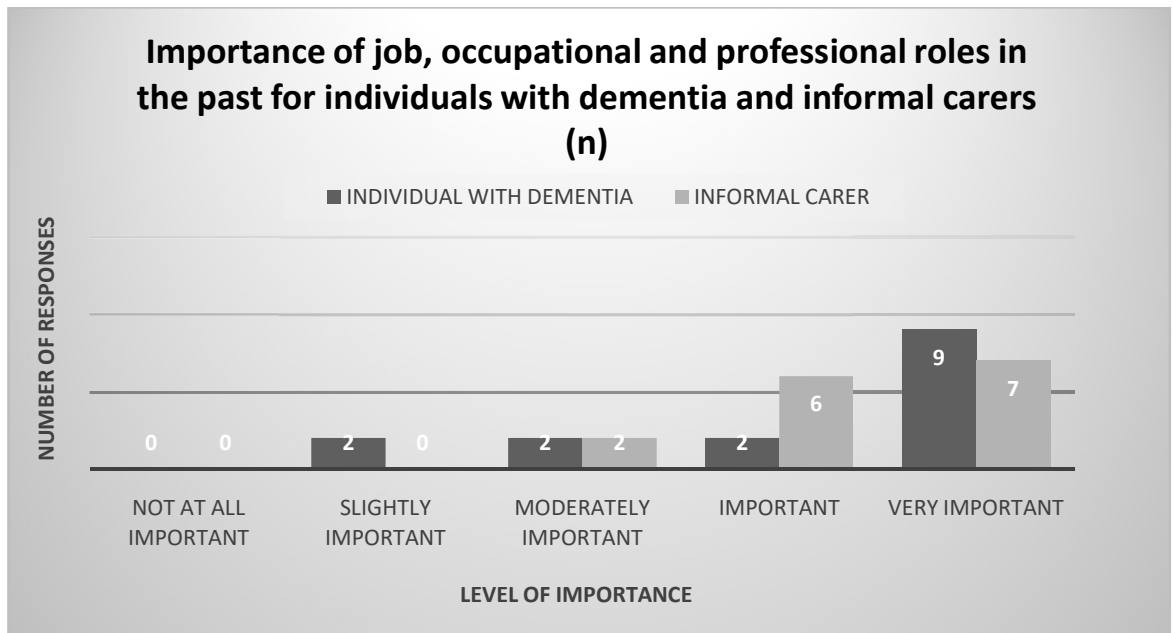
Figure 17 The importance of job, occupational and professional roles in the past for individuals with dementia and informal carers

Summary of participant results from Figure 17:

Individuals with dementia: This group felt predominantly that their previous occupational roles were 'very important' to them in the past (n=9). Only one participant chose 'slightly important' and 'moderately important' each and no one chose that their job role was 'not at all important'.

Informal carers: The informal carers responded by choosing either 'very important' (n=7) or 'important' (n=6).

In summary, for the majority of individuals with dementia and informal carers, there was agreement that previous occupational role for most was 'very important' or 'important, with nine individuals with dementia stating it was 'very important' and seven informal carers agreeing.

The Adapted-SIDQ asked all the participant groups '*How important is this job, occupation or profession to you/your relative/your patient today?*' (Section A, individuals with dementia Q2, informal carer Q6, and formal carer Q3).
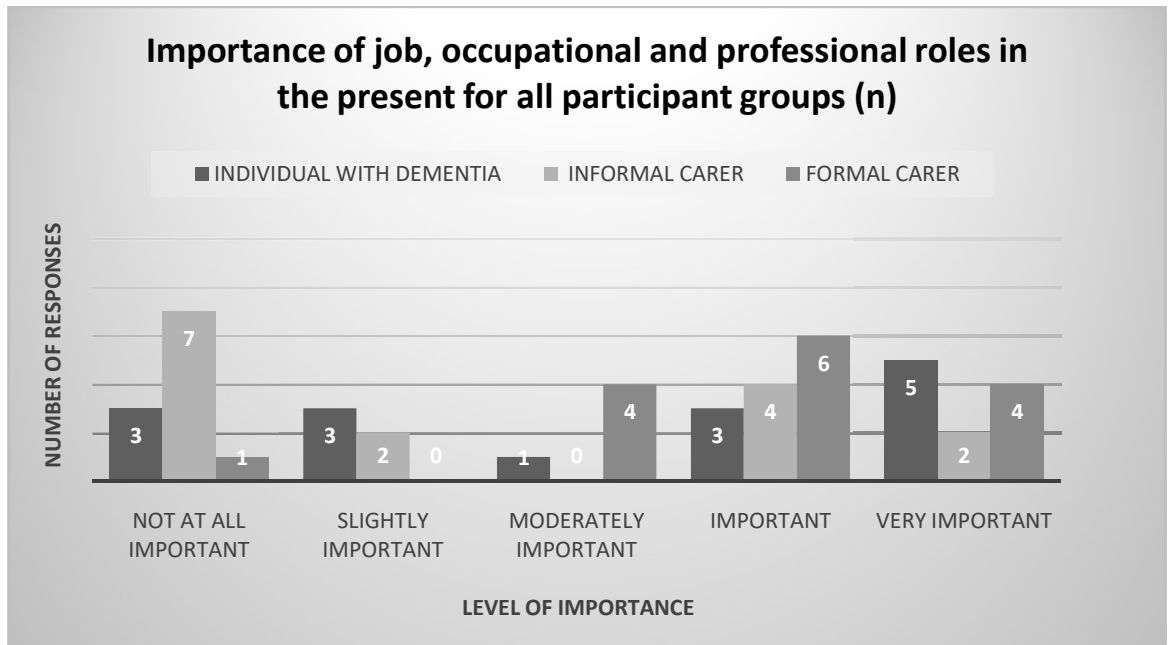
Figure 18 The importance of job, occupational and professional roles for the three participant groups in the present

Summary of participant results from Figure 18:

Individuals with dementia: For this group there was a spectrum of responses, with no dominant choice made. The highest number of patients stated that their job was 'very important' to them in the present (n=5). However, half of the group felt that it was 'moderately important' or less.

Informal carers: The informal carers responded by choosing 'not very important' (n=7) or 'slightly important' (n=2), which was very different from the perspective of those with dementia. Formal carers: This participant group indicated that for the individual with dementia job role was 'important' (n=6) or 'very important' (n=4). Their responses were predominantly positive, whereas the informal carers were

mostly negative. What cannot be determined from these results is whether the formal carers were making assumptions about this self-identity theme aspect or they actually knew that the individual's occupation was important to them.

Table 11 provides the weighted kappa values for the levels of agreement for job role. In summary, the three participant groups had very different perceptions of how important the individual with dementia's job, occupation or profession was in the present.

Table 11 Comparison and importance levels regarding the level of agreement for job, occupation and professional role between participant groups

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Individual with dementia (PAST) versus Individual with dementia (PRESENT)	κ = 0.407	Moderate level of agreement
Individual with dementia (PAST) versus Informal carer (PAST)	κ = 0.118	Slight level of agreement
Individual with dementia (PRESENT) versus Informal carer (PRESENT)	κ = 0.144	Slight level of agreement
Individual with dementia (PRESENT) versus Formal carer (PRESENT)	κ = 0.130	Slight level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = 0.097	Slight level of agreement

Summary of participant results from Table 11:

<u>Individuals with dementia</u>: In the present, the individuals with dementia changed their position on how important their job, occupation or professional role is compared to in the past. Only three participants with dementia stated it remained 'very important' today, compared to nine participants who had previously reported it had played a 'very important' role in the past. The level of importance was reduced to 'not at all important' for three participants with dementia, or 'slightly important' (n=3).

The weighted kappa based extent of agreement between the individuals with dementia when asked about how important their job was in the past and what it meant to them in the present had a kappa value of 0.407, which represents a 'moderate' agreement level, which can be interpreted as the preservation of this domain of self-identity from the past to the present. The level of agreement between the individual with dementia in the past and the informal carer in the past was also only 'slight', with a kappa value of 0.118.

The level of agreement between what the individuals with dementia thought of how important their job role was in the present and the informal carer in the present had a benchmark value of 'slight' level of agreement, with a kappa value of 0.144.

Informal carers: For the informal carers, there were many differences between the past and present, indicating the greatest change in perception of importance of job role for those individuals with dementia. There were seven informal carers who felt that the job role was 'very important' in the past, but this changed to seven participants thinking it was 'not at all important' in the present.

Formal carers: Formal carers indicated that, in the present, job role was either 'moderately important' 'important' or 'very important'; with only one formal carer stating it was 'not at all important'. The formal carers as a cohort reported that job role was important for the individual with dementia, which was not supported by the other two participant groups. This is possibly due to the Registered Nurses acknowledging the importance of past job role for the individual, and also how this is used as a method of engaging the individual with dementia to talk about themselves when developing a therapeutic relationship. Utilising their mental

health nursing skills such as communication skills to actively engage and build rapport is a vital skill, and using previous role is one such method.

In summary, whilst individuals with dementia retained a sense of importance from their previous job, occupation or profession from the past to the present. More informal carers felt that this was not the case; with many more suggesting it was not at all important. More than twice what was expressed by individuals with dementia felt that previous jobs were now not important at all, whilst for individuals with dementia the importance had decreased but was not entirely removed.

The results of the weighted kappa levels of agreement for the importance of job role, as obtained through the Adapted-SIDQ, suggest that the extent of agreement between the participant groups are all 'moderate' or less.

In the Adapted-SIDQ, the informal carers were asked '*In the years that your relative worked in this job what was his/her attitude towards this job, occupation or profession*?' (Section A, Q9) and '*What is his/her attitude towards this job, occupation or profession today*?' (Section A, Q10).
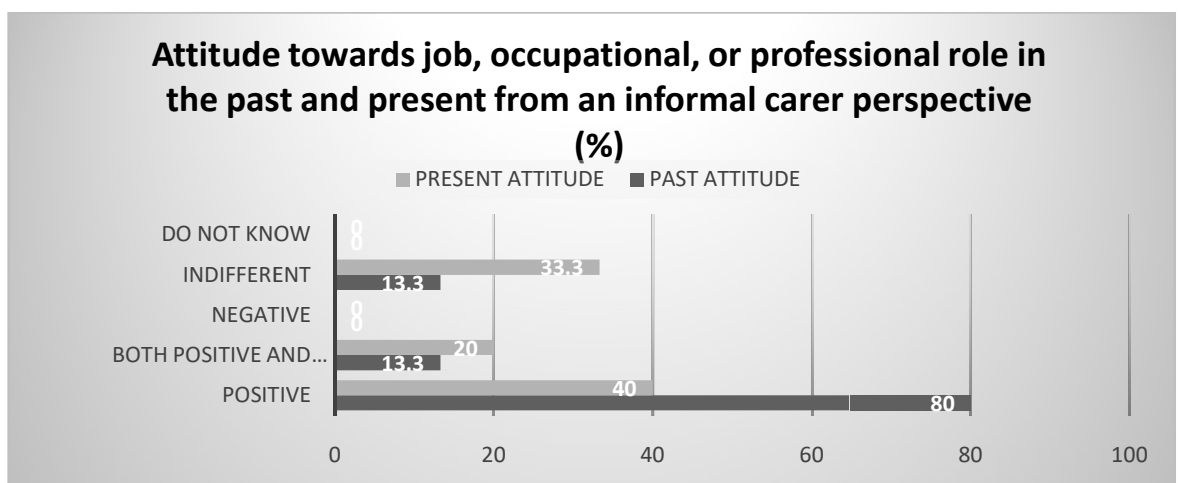
Figure 19 Informal carers perception of their relative with dementia's attitude towards their job, occupation or profession in the past and present

Summary of results from Figure 19:

This question sought to determine the informal carers' understanding of their relatives' attitude towards their job, occupation or professional role in the past and present. In the past, the majority of informal carers reported that it was positive, with 80% choosing that category. However, 13.3% of informal carers stated that individuals with dementia were 'indifferent' to their job role. Comparisons can be made regarding the informal carer's perception of the relative importance of job, occupation and professional role in the past and present. Answers to this question may provide insight into the level of agreement between the person living with dementia and the understanding, or not, of the importance of this area of self-identity. Informal carers reported a change in attitude between the past and present with regards to job role. The informal carer's perception of what is important to their relative with dementia could negatively impact their ability to engage their relative with this aspect of their lives when reminiscing or remembering past aspects. The informal carers reporting 'positive' attitude from those with dementia regarding their job role changed from 80% in the past to only 40% in the present, and the levels of indifference rose from 13.3% in the past to 33.3% in the present.

In the Adapted-SIDQ, the formal carers were asked '*In your opinion, what is his/her attitude towards this job, occupation or profession?*' (Section A, Q6).

Figure 20 Formal carers perception of the individual with dementia's attitude towards their job, occupation or profession today

Summary of results from Figure 20:

By comparing the attitude of those individuals with dementia towards their job, occupation and professional role in the present and with what the formal carers thought, the results could imply how well the formal carers knew those patients with dementia. As part of their role as a Named Nurse, Registered Nurses on the ward can help contribute to increased patient-centred care, individualised treatment pathways, and ensure that the pathway is less fragmented. Central to this role is an awareness of who their patient is; a trusting relationship to understand and empathise with them. This is only possible if pertinent information is gathered about the patient, including past job roles.

Comparison between the formal carer and informal carer would again determine the level of knowledge held by these carers about the individual with dementia. The formal carers indicated that 53.3% of their patients had a positive attitude towards their job role, with low levels of indifference (n=1); however, 20% signposted they did not know. There is a large gap between levels of indifference

between the formal and informal carers (26.6%) signifying a discrepancy on what both these carer groups felt was important to those with dementia.

Table 12 Levels of agreement between informal and formal carers with regard to attitude of those with dementia towards aspects of job, occupational and professional role

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Informal carer (PAST) versus Informal carer (PRESENT)	κ = 0.128	Slight level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = 0.435	Moderate level of agreement

Table 12 summarises the kappa based extent of agreement between the informal carer in the past and the informal carer in the present, which had a weighted kappa value of 0.128 representing a 'slight' agreement level. The level of agreement between the informal carer in the present and the formal carer in the present had a value of κ = 0.435, also indicating a 'moderate' agreement. This indicated that both participant groups had a similar level of understanding of what they thought the individual with dementia's attitudes towards their previous occupational roles were.

4.2.2 Family relationship roles

The Adapted-SIDQ asked the individual with dementia '*How important was this relationship [mentioned in Q1] to you in the past?*' (Section B, Q7) and the informal carer '*How important is this relationship to him/her in the past?*'(Section B, Q2).
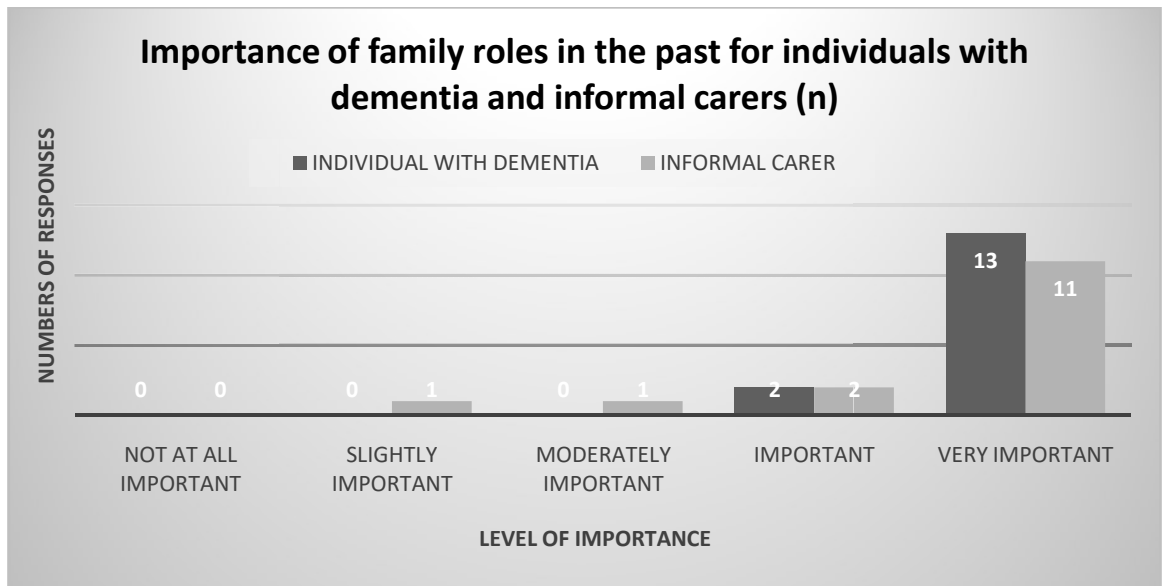
Figure 21 The importance of family roles for the individual with dementia and informal carers in the past

The Adapted-SIDQ asked each participant group about the importance of the family relationships they had identified in the present (Section B, individual with dementia Q8, informal carer Q3, and formal carer Q5).
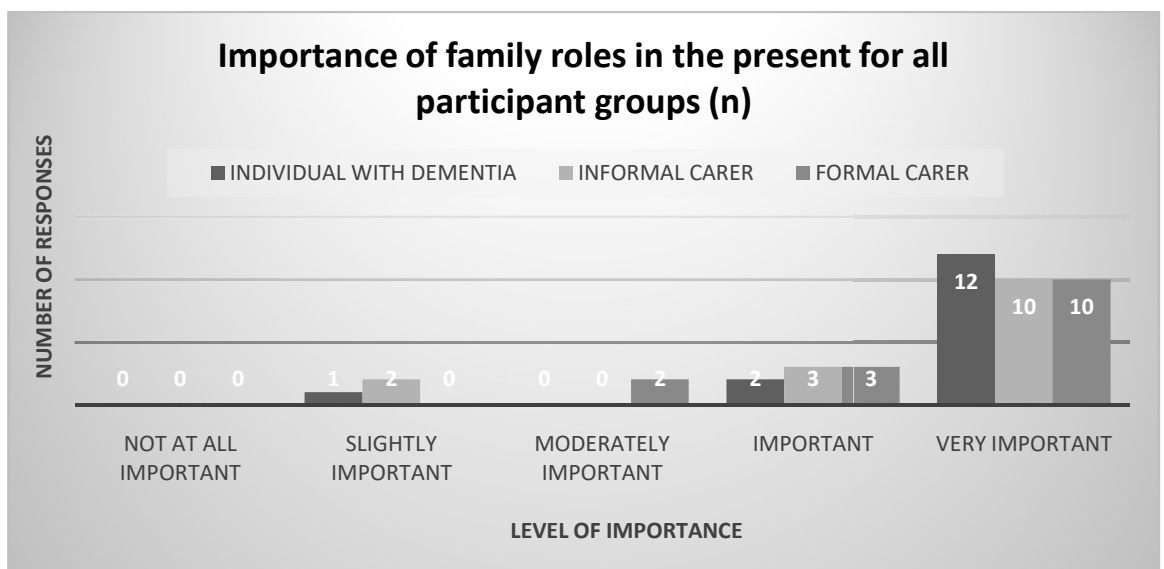
Figure 22 The importance of family roles for the participant groups in the present

Summary of participant results from Figure 22:

All three participant groups (individuals with dementia, their informal carers and formal carers) felt that family relationships were 'very important' in the present. This was the self-identity theme where there was the highest indicated level of agreement as per the graph in Figure 22.

Table 13 Relative importance regarding the level of agreement of family role between participant groups

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Individual with dementia (PAST) versus Individual with dementia (PRESENT)	κ = 0.227	Fair level of agreement
Individual with dementia (PAST) versus Informal carer (PAST)	κ = -0.071	Less than chance level of agreement
Individual with dementia (PRESENT) versus Informal carer (PRESENT)	κ = 0.407	Moderate level of agreement
Individual with dementia (PRESENT) versus Formal carer (PRESENT)	κ = 0.054	Slight level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = 0.000	Less than chance level of agreement

Summary of participant results from Table 13:

Individuals with dementia: For the individuals with dementia, the relationships highlighted were predominantly 'very important' in both the past and present. Responses also included 'important' (n=2) and 'slightly important' (n=1).

Following the weighted Cohen's kappa statistical measure, the extent of agreement which received a 'fair' level of agreement for the importance of family roles were between the individual in the past and the individual in the present (κ = 0.227), but in the present, the individual with dementia and the informal carer in the present (κ = 0.407) had a 'moderate' level of agreement.

<u>Informal carers:</u> Informal carers stated that family relationships were equally important in the past and present, with little difference in their perspectives.

<u>Formal carers:</u> The formal carers indicated that the relationships of those with dementia were predominantly important in the present (n=10), with three stating it was 'important' and two stating it was 'slightly important'. This reflects the perception of the Registered Nurse and how they recognise how important the informal carer's role is within the networks of those with dementia. Through recognising the importance of family members it ensure that the nursing staff foster those relationships and utilise them when caring for the individual with dementia, as reflected in the Triangle of Care (RCN, 2013).

The results of the weighted kappa level of agreement for the importance of family roles amongst the participant groups suggested that the extents of agreement were all 'moderate' or lower. The informal carers were asked '*What do you feel is his/her attitude toward this relationship in the past?'(Section B, Q6)* and '*What do you feel is his/her attitude toward this relationship today?*' (Section B, Q7).
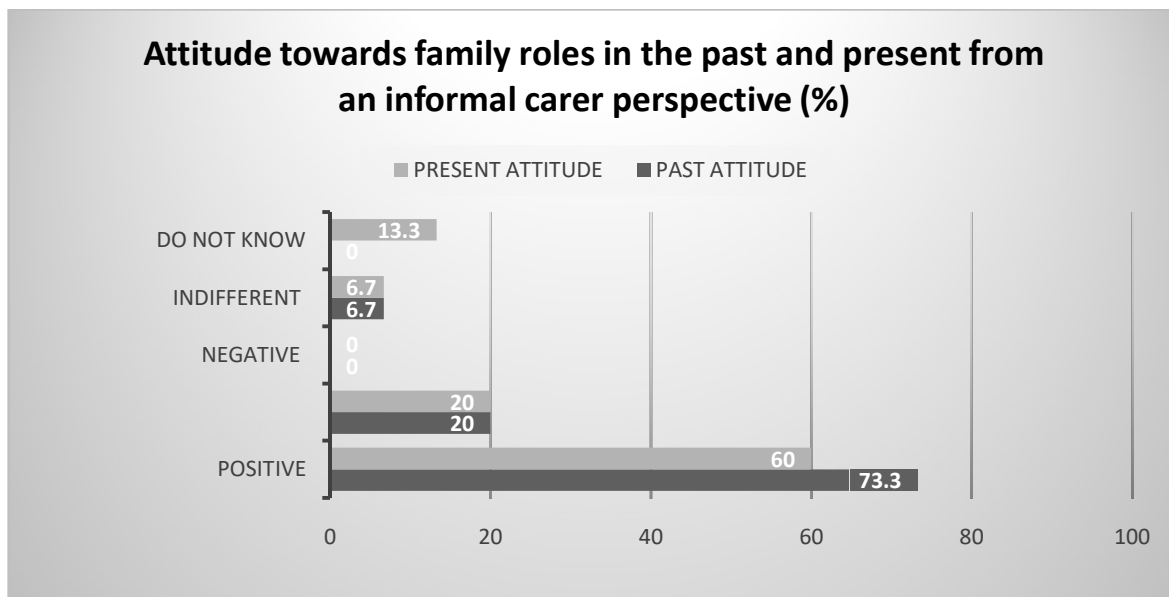
Figure 23 Informal carers perception of the individual with dementia's attitude towards their family roles in the past and present.

Summary of results from Figure 23:

The informal carers reported that individuals with dementia had 'positive' attitudes towards their family roles in the past, with 73% of participants choosing this response; 20% was 'positive and negative', with one participant believing their relative had an 'indifferent' attitude towards family roles in the past.

In the present, informal carers reported an overall 'positive' attitude; with 60% believing those with dementia have a 'positive' attitude towards their relationships. Two informal carers did not know what the individual with dementia's attitude was, which is surprising as informal carers are possibly in the closest position to understand what the person with dementia's thoughts and feelings are in their family relationships.

In the Adapted-SIDQ, the formal carers (Section B, Q7) were asked *'In your opinion, what do you feel is his/her attitude towards this relationship?'*
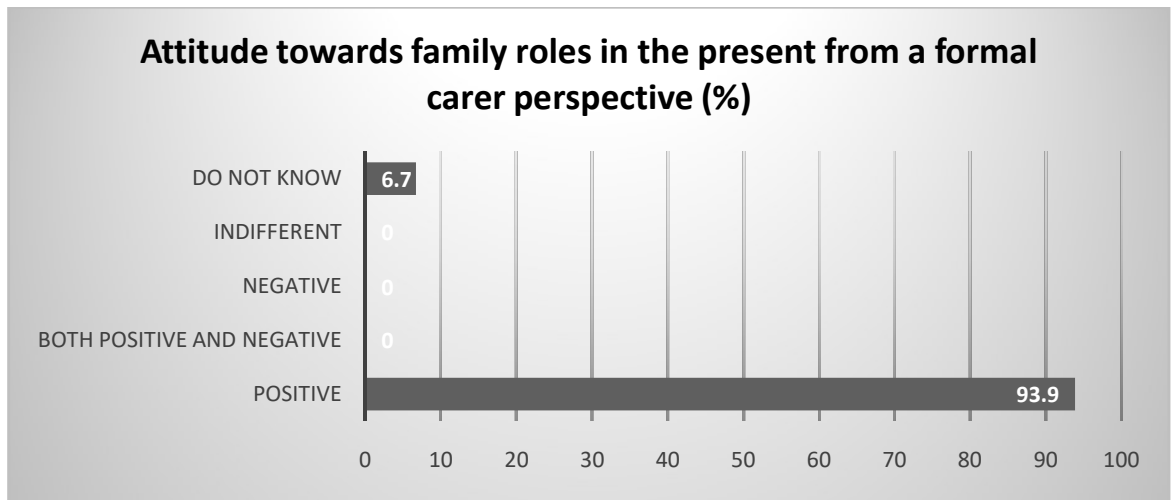
Figure 24 Formal carers perception of the individual with dementia's attitude towards their family roles in the present

Summary of results from Figure 24:

Overall, 93.9% (14/15) of formal carers felt that the individuals with dementia had a 'positive' opinion of their main relationship. One of the formal carers 'did not know', which is surprising as work with people with dementia involves informal carers observing and discussing relationships as part of the admission assessment for the patient. Again this reflects the nurse's recognition of how important family and carer relationships are in the self-identity of individuals living with dementia.

Table 14 Levels of agreement between informal and formal carers with regard to attitude of those with dementia towards aspects of family relationships

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Informal carer (PAST) versus Informal carer (PRESENT)	κ = -0.029	Less than chance level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = 0.280	Fair level of agreement

Table 14 summarises the weighted kappa based extent of agreement between the informal carer in the past and the informal carer in the present, which had a value of – 0.029 representing a 'less than chance' level of agreement according to the Landis and Koch (1977) benchmark scale. The level of agreement between the informal carer in the present and the formal carer in the present had a value of κ = 0.280 indicating a 'fair' level of agreement.

4.2.3 Hobbies and Activities

The questions posed from the Adapted-SIDQ to the individuals with dementia and the informal carer were; '*How important were these hobbies and activities to you in the past*'? and '*How important were these hobbies and activities to him/her in the past*'? (Section C, individuals with dementia, Q2 and informal carer, Q2).
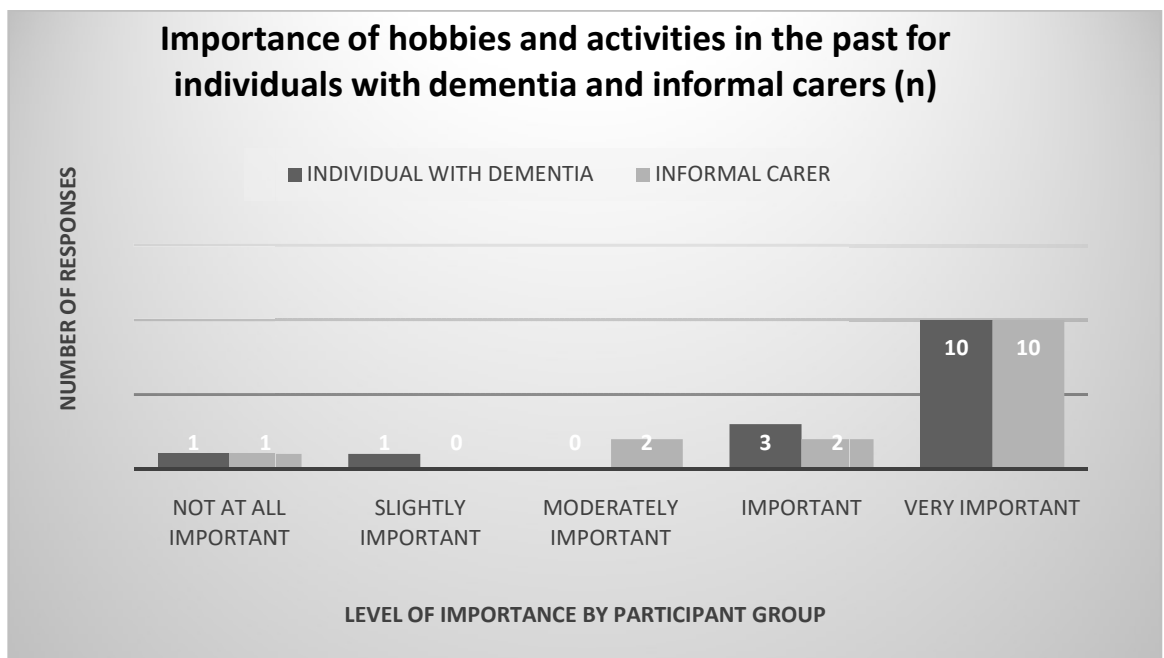
Figure 25 The importance of main hobbies and activities for individuals with dementia according to individuals living with dementia and informal carers in the past

Summary of participant results from Figure 25:

Individuals with dementia: In the past, hobbies and activities were 'very important' for the individual (n=10), whilst one individual with dementia responded 'not at all important' and another 'slightly important'.

Informal carers: Predominantly it was recorded that the hobbies and activities for individuals with dementia were 'important' or 'very important' in the present (1315 participants).

The Adapted-SIDQ asked '*How important are theses hobbies and activities to you today?', 'How important are theses hobbies/activities to him/her today?*', and '*In your opinion, how important are theses hobbies or activities to him/her today?'(*Section C, individual with dementia Q3, informal carer Q7, formal carer Q3).
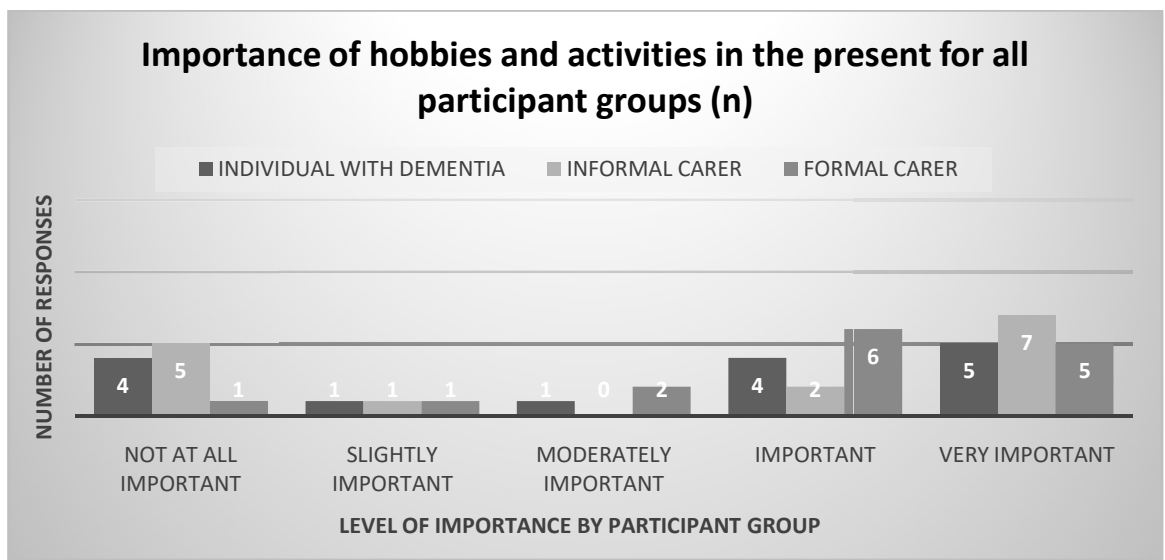
Figure 26 The importance of main hobbies and activities for the three participant groups in the present

Summary of participant results from Figure 26:

<u>Individuals with dementia</u>: The results from this group varied across all the responses, with five participants stating their hobbies and activities in the present were 'very important', yet similarly four individuals with dementia felt that they were 'not at all important'.

<u>Informal carers</u>: Seven of the informal carer group felt that the individual with dementia's hobbies and activities were 'very important' in the present, but five felt they were 'not at all important'.

<u>Formal carers</u>: The responses were across the continuum of importance, but the group predominantly felt it was either 'important' (n=6) or 'very important' (n=5). The Registered Nurses, working with the multi-disciplinary team, often utilise hobbies and activities to provide stimulation and activities whilst assessing cognitive behavioural and mood related aspect of dementia, which reflects their stance of how important knowing this aspect of self-identity is.

Table 15 Relative importance regarding the level of agreement for hobbies and activities

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Individual with dementia (PAST) versus Individual with dementia (PRESENT)	κ = 0.397	Fair level of agreement
Individual with dementia (PAST) versus Informal carer (PAST)	κ = - 0.034	Less than chance level of agreement
Individual with dementia (PRESENT) versus Informal carer (PRESENT)	κ = 0.394	Fair level of agreement
Individual with dementia (PRESENT) versus Formal carer (PRESENT)	κ = - 0.017	Less than chance level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = 0.140	Slight level of agreement

Table 15 summarises the weighted kappa based extent of agreement between the individuals with dementia when asked about how important their hobbies and activities were in the past and what it meant to them in the present which had a weighted kappa value of 0.397, representing a 'fair' agreement level according to the Landis and Koch (1977) benchmark scale. The level of agreement between the individual with dementia in the past and the informal carer in the past had a kappa value of - 0.034 indicating a less than chance level of agreement.

The level of agreement between what the individuals with dementia thought about how important their hobbies and activities were in the present and the informal carer in the present had a benchmark value of 'slight' level of agreement from a kappa value of 0.068.

The results of the kappa levels of agreement for the importance of hobbies and activities as obtained through the Adapted-SIDQ between the participant groups and timeframes suggests that the extent of agreement are all low.

The informal carers were asked *'What is his/her attitude towards these hobbies and activities in the past?'*(Section C, Q6) *and 'What is your relative's attitude towards these hobbies or activities today?'*(Section C, Q7*)*.
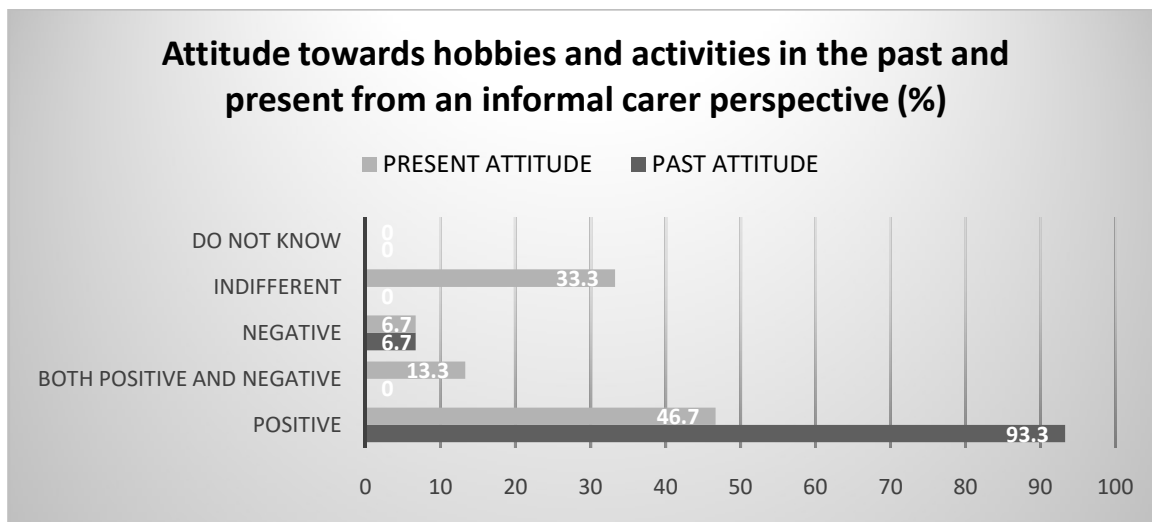
Figure 27 Informal carers perception of the individual with dementia's attitude towards their hobbies and activities in the past

Summary of results from Figure 27:

In the past, the informal carers felt that those with dementia had a 'positive' attitude towards their hobbies and activities. Mostly, the informal carers did not select the lower categories, but one participant chose that those with dementia had a 'negative' attitude. In comparison, in the present the informal carer responses were very different, with the 'positive' response dropping from 93.3% in the past to only 46.7% in the present. Two informal carers thought that the attitude of those with dementia had 'positive and negative' elements, and there appeared to be the perception of indifference to their hobbies and activities from informal carers, with 33.3% choosing this response.

The formal carers were asked *'What is his/her attitude towards these hobbies/activities?'*(Section C, Q7).

Attitude towards hobbies and activities in the present from a formal carer perspective (%)

Category	Value
DO NOT KNOW	6.7
INDIFFERENT	13.3
NEGATIVE	0
BOTH POSITIVE AND NEGATIVE	13.3
POSITIVE	66.7
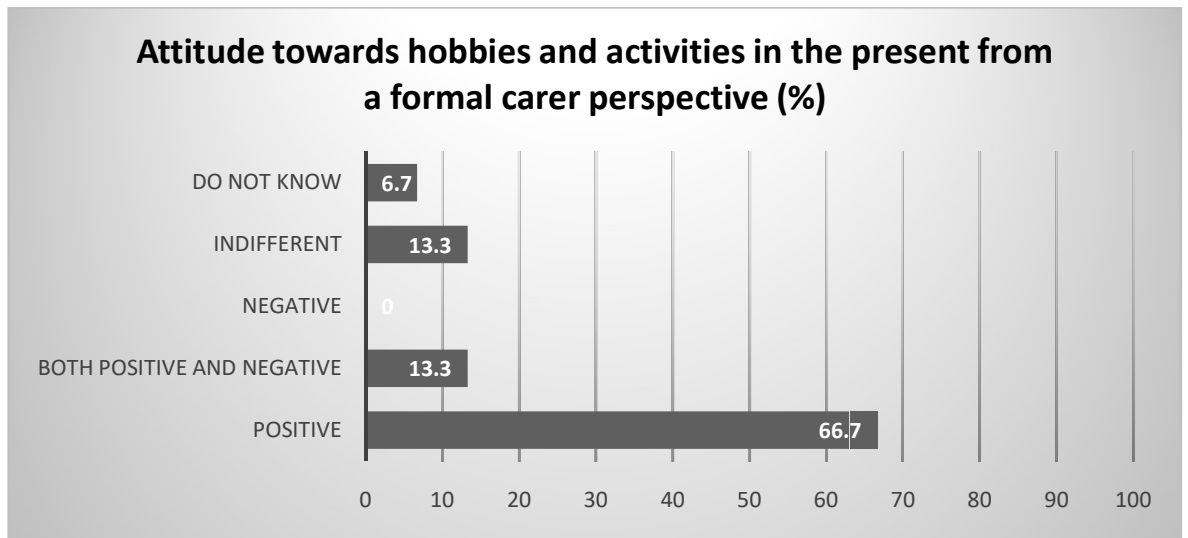
Figure 28 Formal carers perception of the individual with dementia's attitude towards their hobbies and activities in the present

Summary of participant results from Figure 28:

The formal carers felt that those with dementia had an overall 'positive' attitude to the hobbies and activities they engaged in on the ward, with 66.7% choosing this response. There appeared to be some indifference (n=2, 13.3%) and 'positive and negative' attitudes noted (n=2, 13.3%), which may have been related to the types of activities being offered and available within the ward environment.

Table 16 Levels of agreement between informal and formal carers with regard to attitude of those with dementia towards hobbies and activities

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Informal carer (PAST) versus Informal carer (PRESENT)	κ = - 0.098	Less than chance level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = 0.113	Slight level of agreement

Table 16 summarises the weighted kappa based extent of agreement between the informal carer in the past and the informal in the present, which had a kappa value of -0.098 representing a less than chance level of agreement.

The level of agreement between the informal carer in the present and the formal carer in the present had a value of κ = 0.113 indicating a 'slight' level of agreement, suggesting that both participant groups had an understanding of what they felt was important to the individuals with dementia in terms of importance of hobbies and activities.

4.2.4 Personal achievements, attributes and traits

The questions posed from the Adapted-SIDQ to the individuals with dementia were '*How important were these achievements, attributes and traits to you in the past?*'(Section D, Q2) and '*How important are these achievements, attributes and traits to you today?*'(Section D, Q3) and the informal carers '*How important were these achievements or traits to him/her in the past?*'(Section D, Q2) and (Section D, Q3) '*How important are these achievements or traits to him/her today?*'
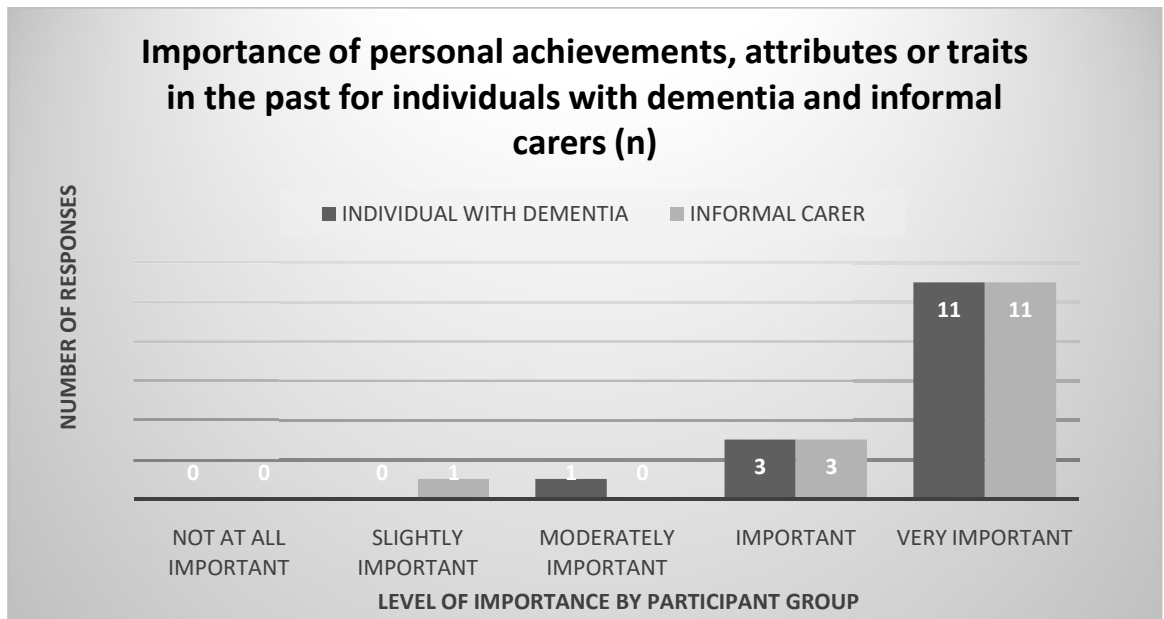
Figure 29 The importance of achievements, attributes and traits for the individual with dementia and informal carers in the past

Summary of participant results from Figure 29:

<u>Individuals with dementia:</u>In the past, the levels of importance of achievement, attributes and traits was 'very important' for 11 out of the 15 individuals with dementia.

<u>Informal carers:</u>In the past, the levels of importance of achievement, attributes and traits was 'very important' for 11 out of the 15 informal carers. Only one informal carer indicated 'slightly important', but all other participants felt that personal achievements attributes, and traits were 'important' or 'very important'.

The Adapted-SIDQ asked '*How important are these personal achievements, attributes and traits to you today?', 'How important are these personal achievements, attributes and traits to him/her today?*', and '*In your opinion, how important are these personal achievements, attributes and traits to him/her*

today?'(Section D, individual with dementia Q3, informal carer Q3, formal carer Q3).
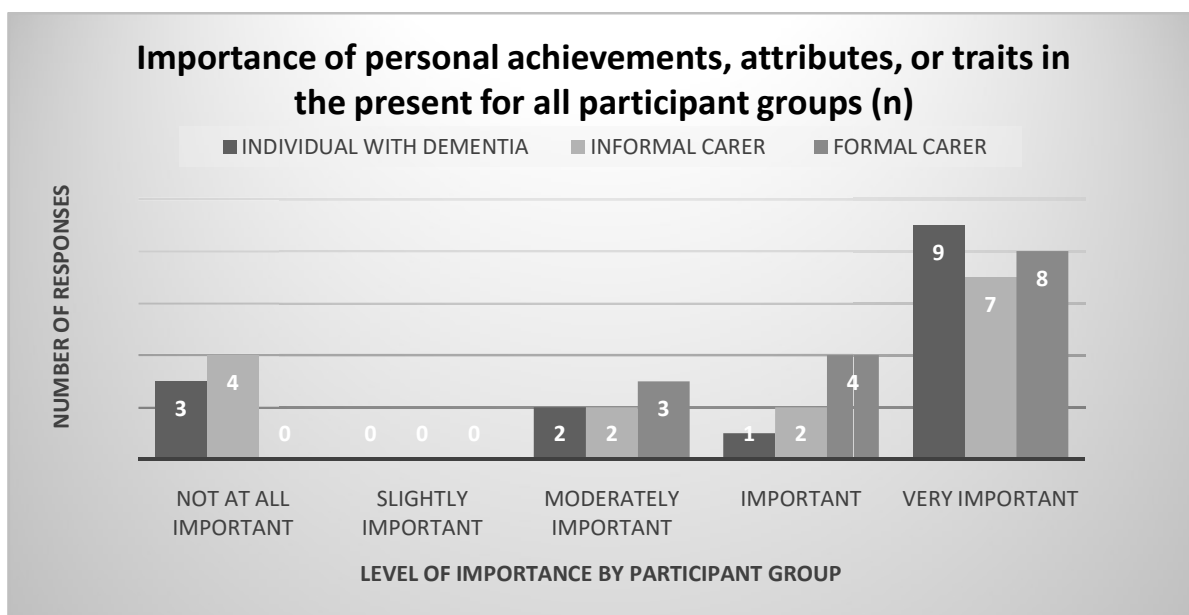
Figure 30 The importance of personal achievements, attributes and traits as per participant group

Table 17 Relative importance regarding the level of agreement of personal achievements, attributes and traits between participant groups

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Individual with dementia (PAST) versus Individual with dementia (PRESENT)	κ = 0.338	Fair level of agreement
Individual with dementia (PAST) versus Informal carer (PAST)	κ = 0.375	Fair level of agreement
Individual with dementia (PRESENT) versus Informal carer (PRESENT)	κ = 0.488	Moderate level of agreement
Individual with dementia (PRESENT) versus Formal carer (PRESENT)	κ = 0.100	Slight level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = 0.248	Fair level of agreement

Summary of participant results from Figure 30 and Table 17:

Individuals with dementia: Nine participants responded that their personal achievements, attributes and traits were 'very important' in the present, but three individuals with dementia felt that they were 'not at all important'. The highest level of weighted kappa extent of agreement identified was between the individuals with dementia in the present and the informal carer in the present with a weighted kappa level of agreement of κ = 0.488, a 'moderate' level of agreement, according to the Landis and Koch (1977) benchmark scale. This suggests that the individuals with dementia were able to remember and recall what was important to them with regard to personal achievements, attributes and traits, with a similarity in response with informal carers. The lowest level of agreement identified was between the individuals with dementia in the present and the formal carer in the present, at only 'slight' level of agreement (κ = 0.100) suggesting that the formal carers have minimal awareness of what is important to those that they are caring for with respect to personal attributes and traits.

Informal carers: Four informal carers reported that personal achievements, attributes or traits were 'not at all important', but seven responded that they were 'very important'.

Formal carers: The range of responses from the formal carers felt that it was 'moderately important' (n= 3), 'important' (n=4) or 'very important' (n=8) that these traits were recognised as significant for those with dementia. However, there were only slight agreements with the informal carers.

The results of the weighted kappa levels of agreement for the importance of personal achievements, attributes and traits between all groups as obtained

through the Adapted-SIDQ suggests that the extents of agreement were moderate to low.

The Adapted-SIDQ asked the informal carers '*What was his/her attitude towards these achievements or traits in the past*?'(Section D, Q6), and '*What is your relative's attitude towards these hobbies or activities today?*'(Section D, Q7).
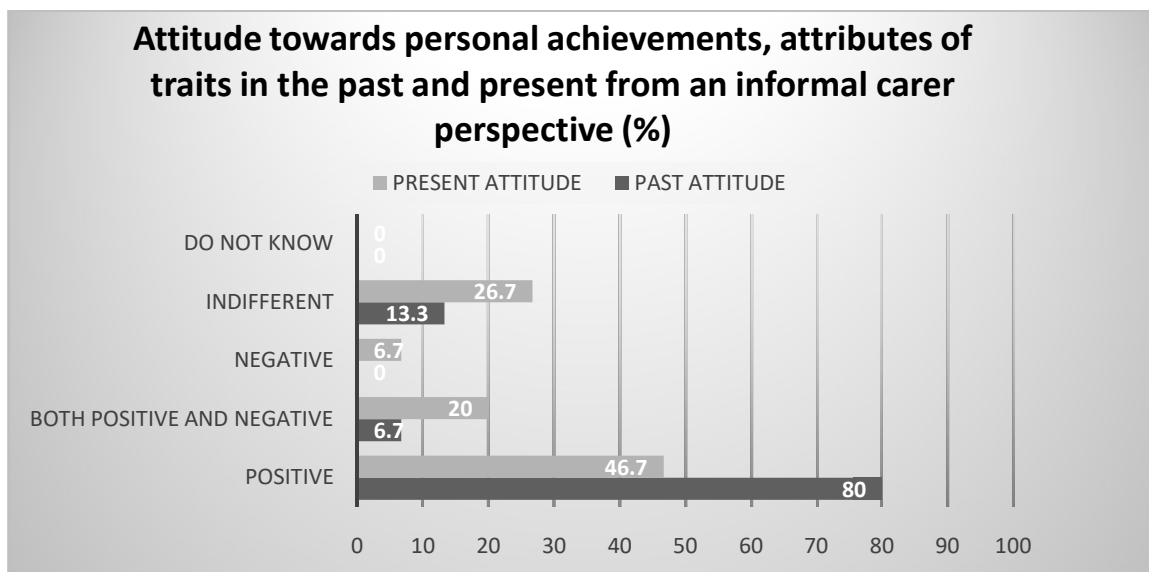
Figure 31 Informal carers perception of the individual with dementia's attitude towards their personal achievements, attributes and traits in the past and present

Summary of results from Figure 31:

The informal carers chose the 'positive' category regarding the individual with dementia's attitude towards personal achievements, attributes and traits in the past, with 80% of participants choosing this category. There was also a feeling of indifference from some informal carers who believed that their relative with dementia held no meaning for these aspects of self-identity. The informal carers felt this 'positive' attitude of 80% in the past decreased to 46.7% in the present, with more indifference (past, 13.3% compared to 26.7% in the present) and

'negative' (0% in the past and 6.7% in the present) attitudes expressed towards their personal achievements, attributes and traits.

The Adapted-SIDQ asked formal carers *'What was his/her attitude toward these achievements, attributes or trait?'*(Section D, Q7).

Attitude towards personal achievements, attributes or traits in the present from a formal carer perspective (%)

Category	Value
DO NOT KNOW	13.3
INDIFFERENT	0
NEGATIVE	0
BOTH POSITIVE AND NEGATIVE	6.7
POSITIVE	80
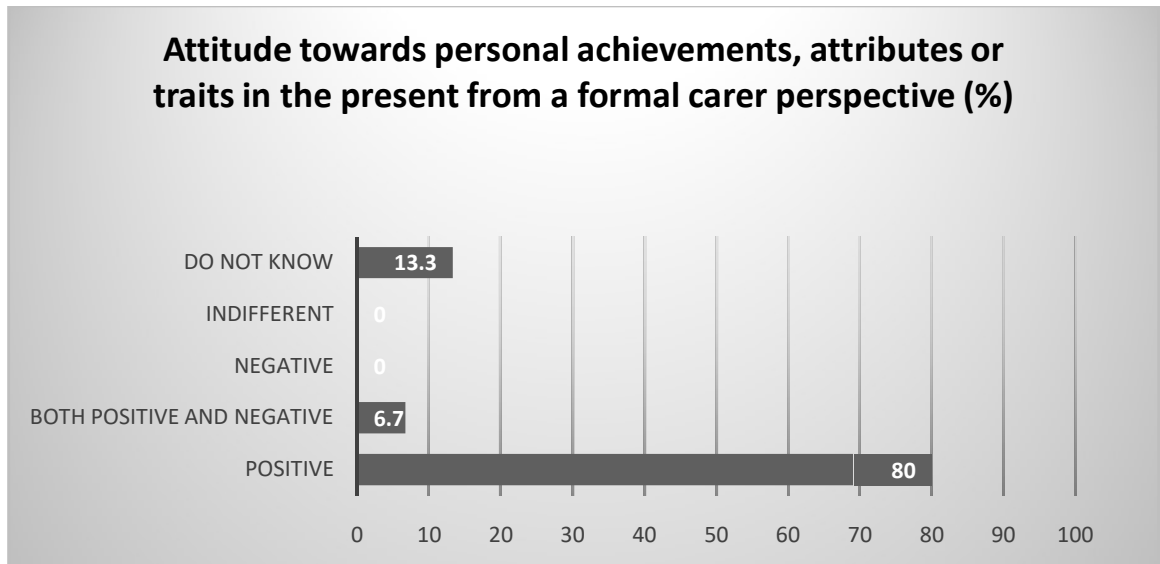
Figure 32 Formal carers perception of the individual with dementia's attitude towards their personal achievements, attributes and traits in the present

Summary of participant results from Figure 32:

In the present, the formal carers felt that those with dementia had an overall 'positive' attitude towards achievements, attitudes and traits, similar to the informal carer perspective in the past.

Table 18 Levels of agreement between informal and formal carers with regard to attitude of those with dementia towards personal achievements, attributes and traits

Participant groups and time frame	Weighted Kappa Value	Weighted Kappa Value Descriptor
Informal carer (PAST) versus Informal carer (PRESENT)	κ = 0.155	Slight level of agreement
Informal carer (PRESENT) versus Formal carer (PRESENT)	κ = - 0.154	Less than chance level of agreement

Table 18 summarises the weighted kappa based extent of agreement between the informal carer in the past and the informal carer in the present, which had a kappa value of 0.155 representing a 'slight' level of agreement.

The level of agreement between the informal carer in the present and the formal carer in the present had a value of $\kappa = -0.154$ indicating a level of agreement, which is less that chance, suggesting that both participant groups had only a minimal understanding of what they felt was important to the individuals with dementia in terms of their personal achievements, attributes and traits.

4.4 The ways that self-identity can be elicited, and how self-identity can be enhanced and the potential impact of this

In order to answer the question 'What, if any, are the ways that different informants think self-identity information can be elicited?' results from the Adapted-SIDQ will be presented. These include the use of an individual's name, behaviours and topics of conversation of those living with dementia across the four self-identity domains.

4.4.1 Individual's name and impact on self-identity

The participant groups were asked *'How would you like the staff to refer to you?'* (Additional questions, individual with dementia, Q1*), 'By which name or title do you think the staff should refer to your relative'* (Questions related to self-identity, informal carer, Q1) or '*By which name/title do you think the staff should refer to the individual with dementia?'*(Questions related to self-identity, formal carer, Q1).

Table 19 Preference in choice of name by participant group

Preferred reference	Participant group		
	Individuals with dementia (n=15) (%)	Informal carer (n=15) (%)	Formal carer (n=15) (%)
By your first name	14 (93.3)	14 (93.3%)	13 (86.7%)
By your nickname	0	0	1 (6.7%)
Mr or Mrs	1 (6.7%)	1 (6.7%)	1 (6.7%)
Professor	0	0	0
Doctor	0	0	0
Other	0	0	0
Do not know	0	0	0

Summary of participant results from Table 15:

Individuals with dementia: All individuals with dementia expressed a preference of how they would like the nursing staff to refer to them. The majority preferred to be referred to by their first name (14/15), with only one male participant preferring to be called by the title of Mister (n=1).

Informal carers: Informal carers predominantly selected what they believed the individuals with dementia would be preferred to be called by their first name.

Formal carers: Formal carers referred to individuals with dementia by their first name as per their preference. They adhered to the wishes of the one participant who preferred to be called Mister. One formal carer reported that a patient would like to be called by their nickname, but this was not the preference chosen by that individual or their informal carer. The Alzheimer's Society (2015) emphasises the need to use a name the individual with dementia recognises and prefers, to convey understanding and respect to that individual. The formal carer had used a name which was not preferred nor recognised by the individual, potentially detracting from their selfhood.

4.4.2 Behaviours and topics of conversation of those with dementia

In order to elicit aspects of self-identity of individuals with dementia, it was possible to explore the perspectives of both informal and formal carers and what they believed the impact of behaviours and topics of conversation had on their relatives.

4.4.2.1 Job, occupational or professional role

The questions posed from the Adapted-SIDQ to the informal (Section A, Q7) and formal carers (Section A, Q4) was *'How often does s/he talk about their job, occupation or profession?'*
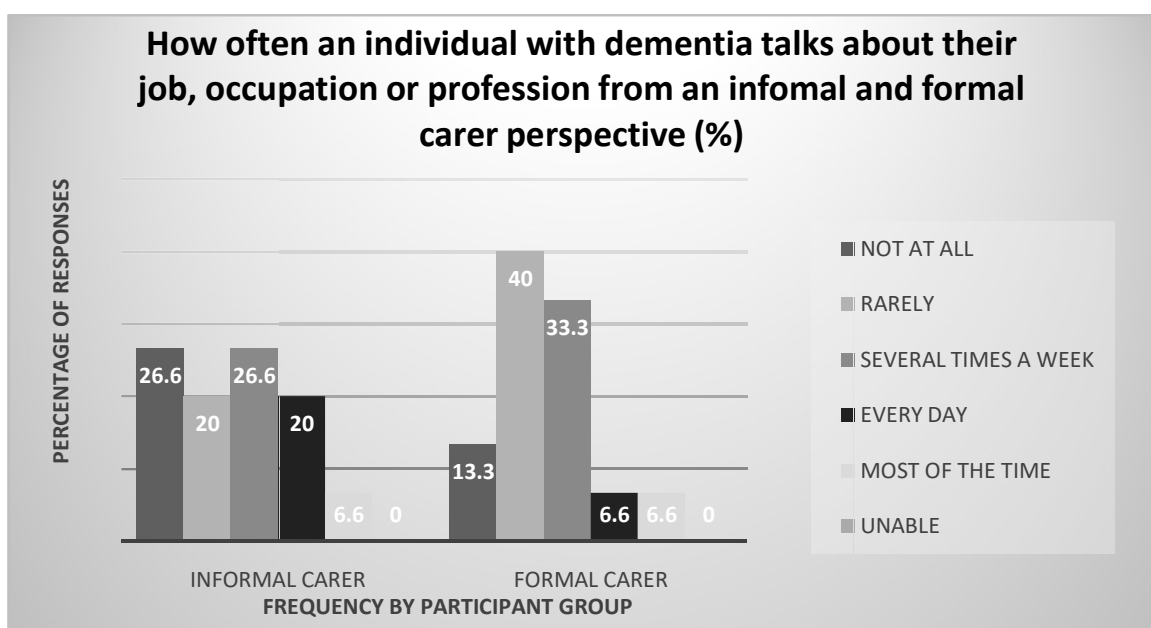
Figure 33 How often an individual with dementia talks about their job, occupation or profession from an informal and formal carer perspective

Summary of results from Figure 33:

Informal carers: The informal carers reported that individuals with dementia spoke about their past occupations 'rarely' (20%) or 'not at all' (26.6%). Only one informal carer stated that the individual spoke about their past job role 'most of the time'.

This individual previously worked within the grounds of the hospital where he was now an in-patient, and he consistently used this as a conversation opener with staff and visitors to the ward.

Formal carers: The formal carers felt that individuals with dementia did not tend to talk about their past job, occupation or profession, with 40% stating those with dementia 'rarely' spoke about their past job. What was unclear is whether those patients who spoke about their job roles 'several times a week' (33.3%) were prompted by the nursing staff or spoke about their past job roles spontaneously.

The question posed from the Adapted-SIDQ to the informal (Section A, Q8) and formal carers (Section A, Q5) was '*How often does his/her behaviour show that this was his/her job, occupation or profession?*'
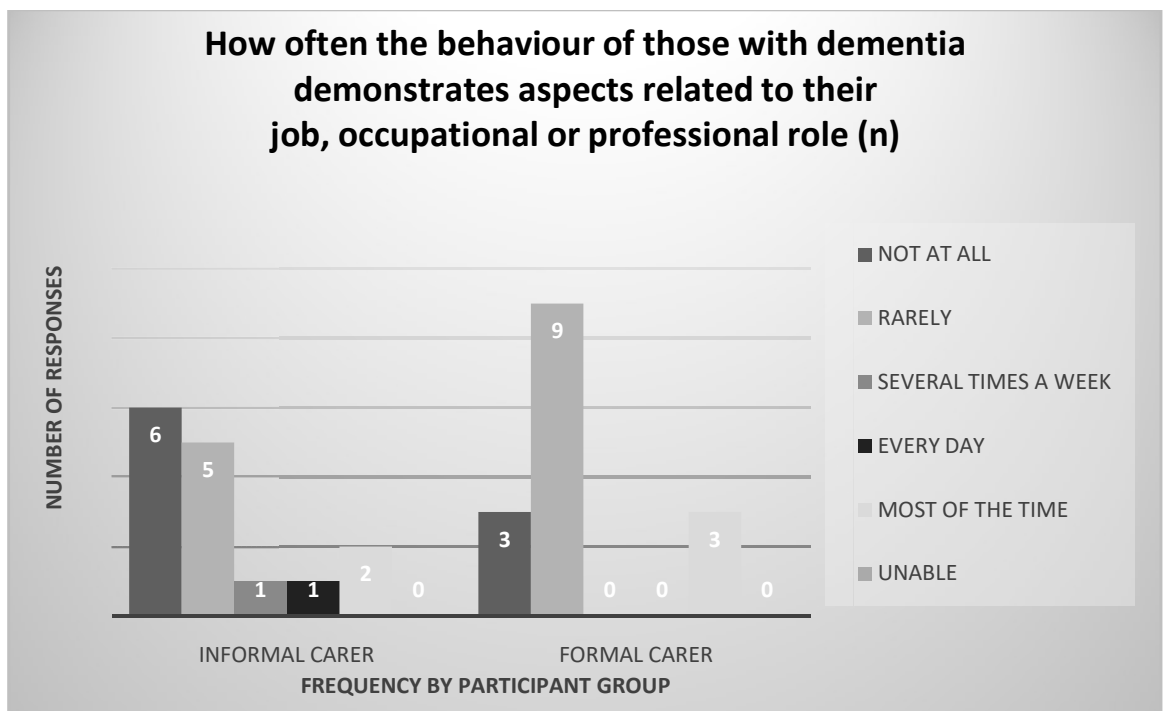
Figure 34 How often the behaviour of those with dementia demonstrates aspects related to their job, occupation or profession

Summary of results from Figure 34:

<u>Informal carers</u>: The majority (n=11/15) of informal carers reported that the behaviour of those with dementia 'did not display' (n=6) or 'rarely displayed' (n=5) aspects of their previous job, occupational or professional role.

<u>Formal Carers</u>: Similarly, nine formal carers reported that the behaviour of those with dementia 'rarely' displayed aspects of their past job role or 'not at all' (three participants). The data reports that past job role, occupation or profession had little impact or influence on the individual with dementia's behaviour at the time of the study.

4.4.2.2 Family relationship roles

The Adapted-SIDQ asked the informal carers (Section B, Q4) and formal carers (Section B, Q4) '*How often does s/he talk about these relationships?*', relating to those relationships they had earlier indicated were important to them.
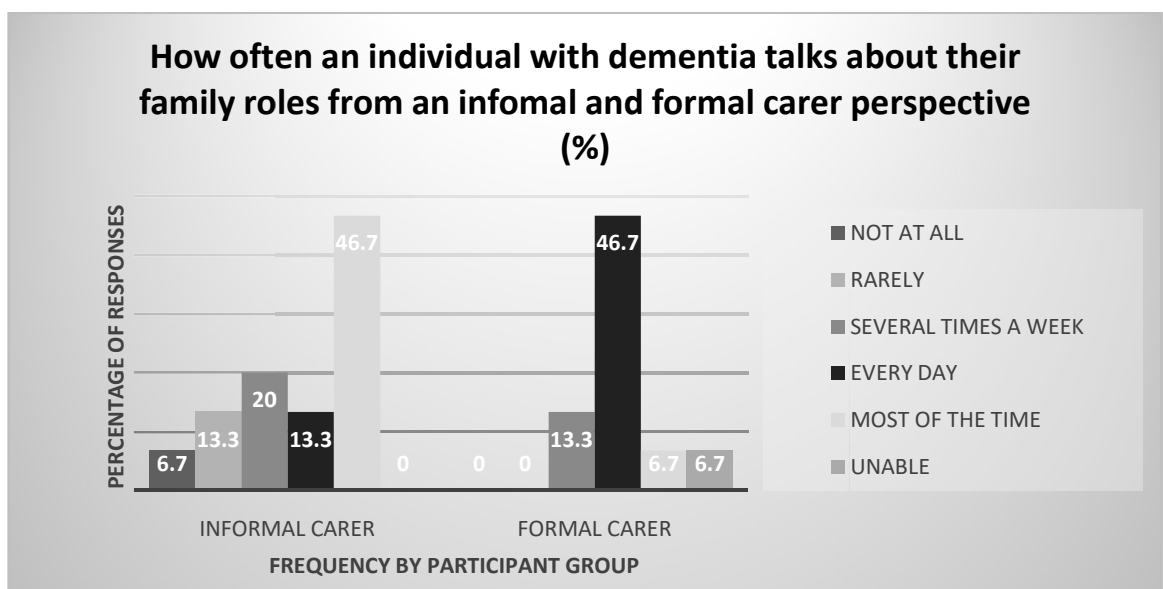
Figure 35 How often a person with dementia talks about their relationships from an informal and formal carer perspective

Summary of results from Figure 35:

Individuals with dementia: From earlier questions in the Adapted-SIQ, it was established that family relationships of those individuals with dementia were very important. These relationships were talked about to varying degrees by those with dementia. Of all the participants with dementia, there were none who were not able to talk about what they considered to be their most important relationships.

Informal carers: Informal carers reported that 46.7% of the individuals with dementia spoke 'most of the time' about family members, with two patients talking about these relationships 'every day' (13.3%), or 'several times a week' (20%).

Formal carers: In comparison, one of the formal carers felt that one of the participants was 'unable' to talk about these relationships due to communication impairments. The formal carers also reported that 46.7% of the individuals with dementia spoke about their family relationships 'every day', but stated that 13.3% of the individuals with dementia spoke of them 'several times a week'. This indicated that this aspect of self-identity was not only an important aspect of the individual's self, but formed the basis of much of their interaction.

Figure 35 demonstrates that those people with dementia often talk about what they consider to be their important relationships, with almost all the informal carer participants confirming that they did talk about family.

There were similarities between the two participant groups in that the informal carers spent most of the time throughout their visit to the hospital talking about family members, as this is often a topic which is important to those with dementia (Figure 35). Formal carers noted that the patients with dementia talked about

family members 'every day' or 'nearly every day'. This topic of conversation is used as a way to positively engage those with dementia, which can often provide the individual with some support and comfort in discussing a familiar and important topic to them. The variation between formal and informal carers is possibly due to their families not observing the patient everyday unlike the nursing staff.

The Adapted-SIDQ asked the informal (Section B, Q5) and formal carers (Section B, Q6), *'How often does his/her behaviour show that these were his/her most important relationship?'*
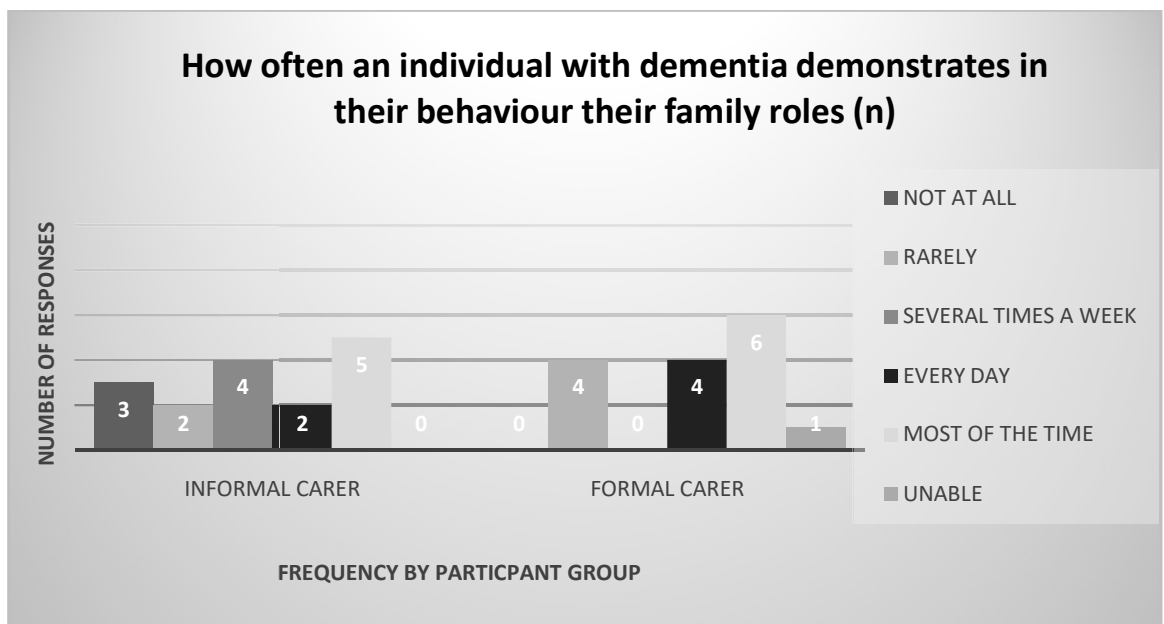
Figure 36 How often the behaviour of those with dementia demonstrates aspects related to their relationships

Summary of results from Figure 36:

<u>Informal carers</u>: The most commonly reported response for informal carers for whether the individual with dementia's behaviour showed aspects related to their important relationships was the 'most of the time' response, with five informal

carers indicating this was observed in the person's behaviour. Three informal carers stated 'not at all'.

Formal carers: The most commonly reported response for formal carers for whether the individual with dementia's behaviour showed aspects related to their important relationships was the 'most of the time' response, with six formal carers indicating this was observed in the person behaviours. For the formal carers, they observed behaviours every day in persons with dementia which indicated their important relationships. One formal carer stated that they were 'unable' to observe if an individual with dementia demonstrated their familial relationship. Formal carers did not choose the response 'not at all'.

4.4.2.3 Hobbies and Activities

The question posed from the Adapted-SIDQ to the informal (Section C, Q4) and formal carers (Section C, Q4) was *'How often does s/he talk about these hobbies or activities?'*
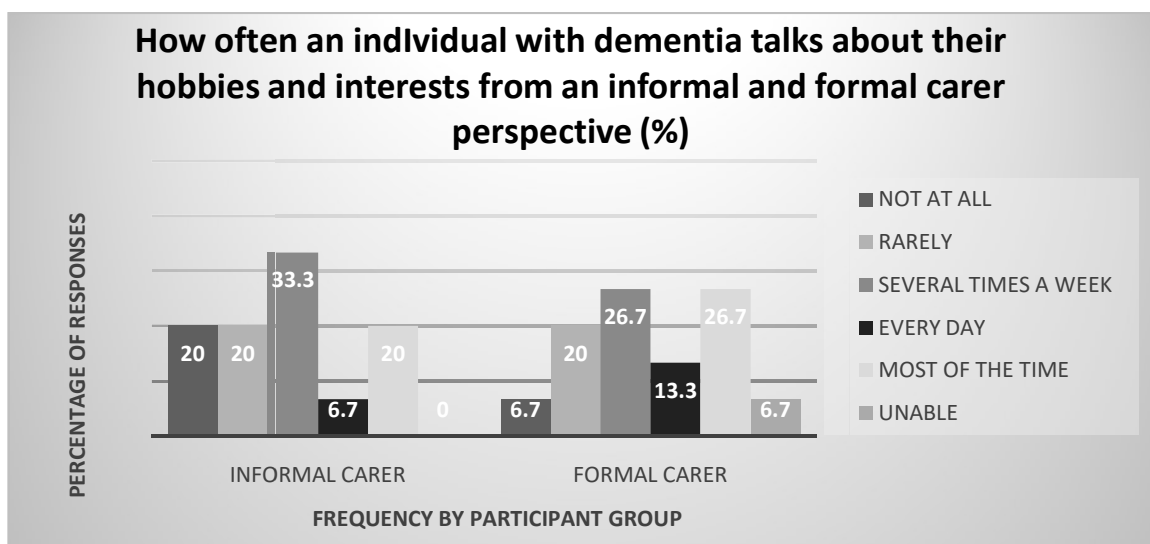
Figure 37 How often an individual with dementia talks about their hobbies and activities from an informal and formal carer perspective

Summary of participant results from Figure 37:

Informal carers: The informal carers reported that individuals with dementia spoke about their preferred hobbies and leisure activities 'several times a week' (33.3%), and 'most of the time' was indicated by 20% of the participants. However, 40% of responses were negative choices on the scale in that the informal carers thought that the individuals with dementia either didn't speak about their hobbies (20%) or rarely did (20%). However, the questionnaire did not provide prompts for explanations as to how this was demonstrated in their behaviour.

Formal carers: In contrast, the formal carers felt that individuals with dementia talked about their hobbies 'most of the time' or 'several times a week' (both 26.7%). One formal carer felt that due to communication impairments the individual with dementia was 'unable' to talk about their hobbies or interests, but the informal carer did not feel that this was the case, and was able to understand the individual with dementia's speech about their interests.

The question posed from the Adapted-SIDQ to the informal (Q5) and formal carers (Q5) was '*How often does his/her behaviour show that these were his/her hobbies or leisure activities?*'
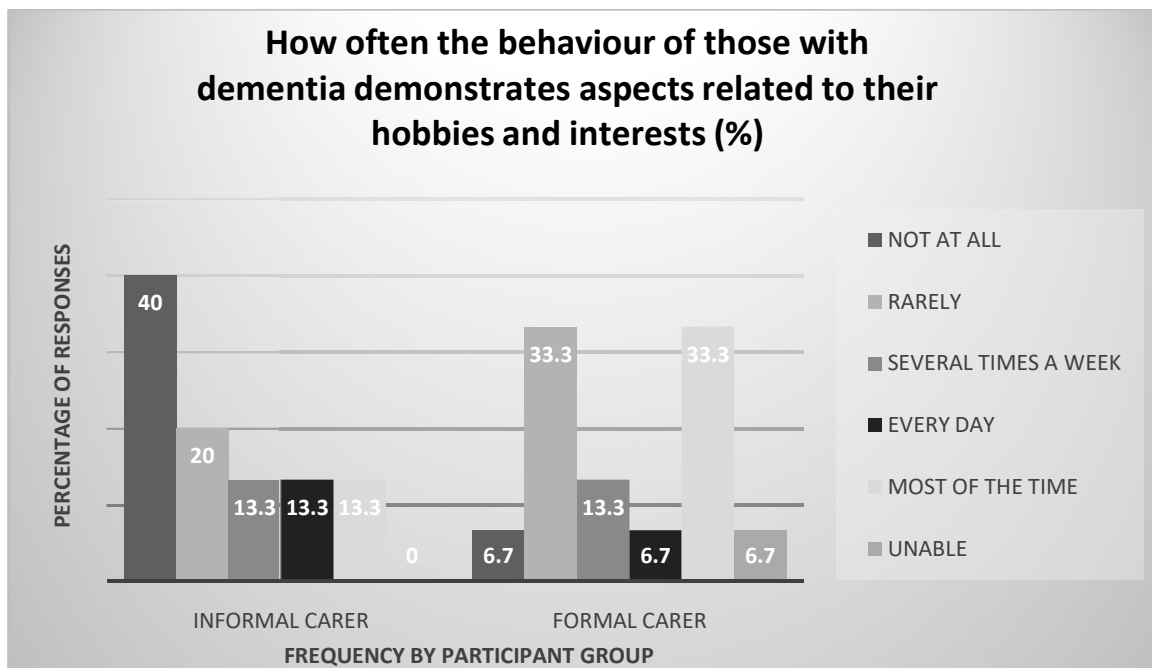
Figure 38 How often the behaviour of those with dementia demonstrates aspects related to their hobbies and interests

Summary of participant results from Figure 38:

Informal carers: The majority of informal carers (40%) did not observe any behaviour in their relatives that demonstrated the maintenance of their hobbies and activities, followed by 'rarely' at 20%, and some behaviours were observed by informal carers ranging from 'most of the time' to 'several times a week'.

Formal carers: 33.3% felt that for some individuals with dementia, their behaviour demonstrated aspects of their preferred hobbies and activities 'most of the time'. Similarly, other formal carers felt that this was only demonstrated 'rarely' (33.3%).

4.4.2.4 Personal achievements, attributes or traits

The Adapted-SIDQ posed the question for the informal (Section D, Q4) and formal (Section D, Q4) carers '*How often does s/he talk about these achievements?*'
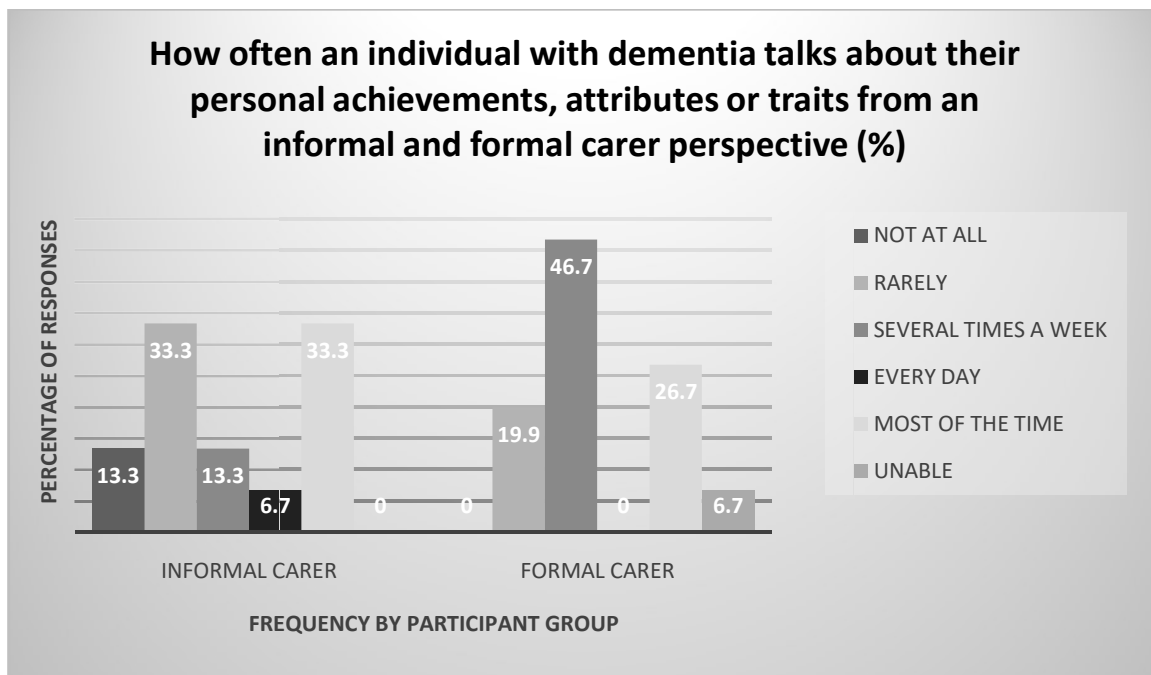
Figure 39 How often an individual with dementia talks about their achievements, attributes or traits from an informal and formal carer perspective

Summary of results from Figure 39:

Informal carers:The informal carers felt that those with dementia spoke about their achievements, attributes and traits 'most of the time', with 33.3% choosing this response.

Formal carers: In comparison, the formal carers felt that achievements were spoken about more indicating 'several times a week' at 46.7%. Responses from the formal carers indicated that 6.7% were 'unable' to talk about these traits but interestingly the informal carers did not choose this option.

The question posed from the Adapted-SIDQ for the informal carer (Q5) and formal carer (Q5) was *'How often does his/her behaviour show that this was his/her most important achievement, attribute or trait?'*
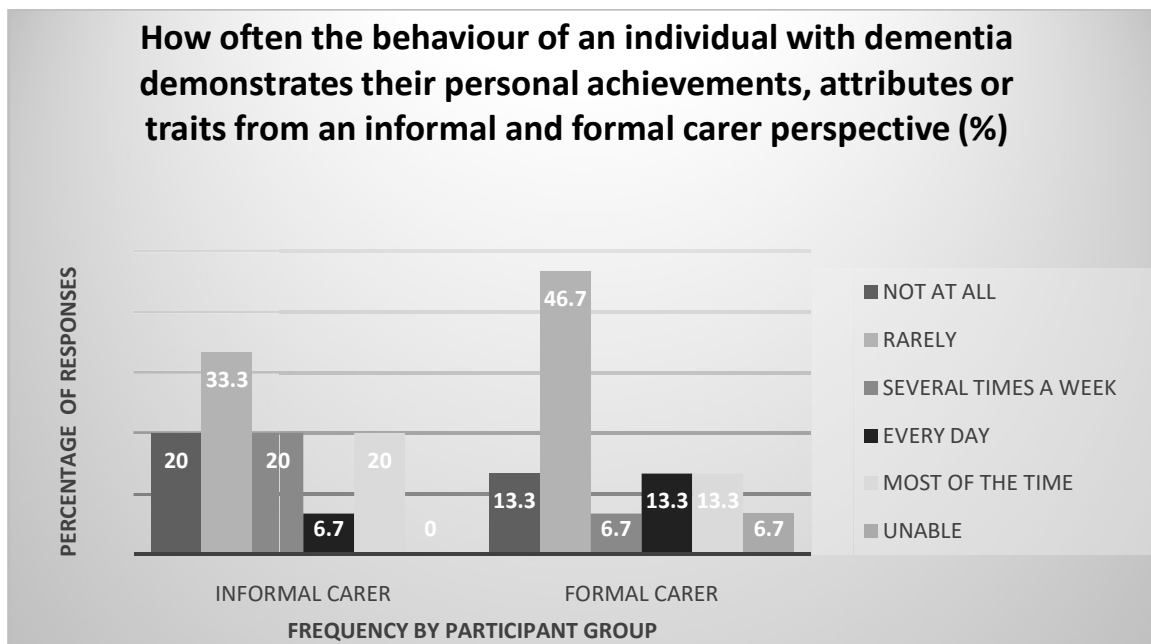
Figure 40 How often the behaviours of an individual with dementia demonstrates their personal achievements, attributes or traits from an informal and formal carer perspective

Summary of results from Figure 40:

Informal carers: There was a range of responses for the informal carer group, with at least one person choosing each category on whether those with dementia demonstrate behaviours associated with their achievements, attributes or traits. Overall, 'rarely' was most chosen with 33.3% opting for this but 'not at all', 'several times a week' and 'most of the time' were chosen by 20% of informal carers.

Formal carers: Formal carers also 'rarely' observed behaviours in those with dementia which reflected their achievements, attributes or traits, with 46% of them choosing this category. 6.7% were unable to observe this behaviour from the formal carers and again this was not a category chosen by informal carers.

4.4.3 Activities to potentially enhance self-identity in individuals with dementia

In order to answer the question *'What, if any, are the ways that different informants perceive self-identity can be enhanced and what is the potential impact of this?'*, the formal and informal carers were asked to explore whether self-identity could be enhanced in individuals with dementia and, if so, by what means these could be established.

The question from the Adapted-SIDQ (Questions related to self-identity, informal and formal carer, Q8) was '*Is it possible to enhance feeling of self-identity in individuals with dementia*?'.
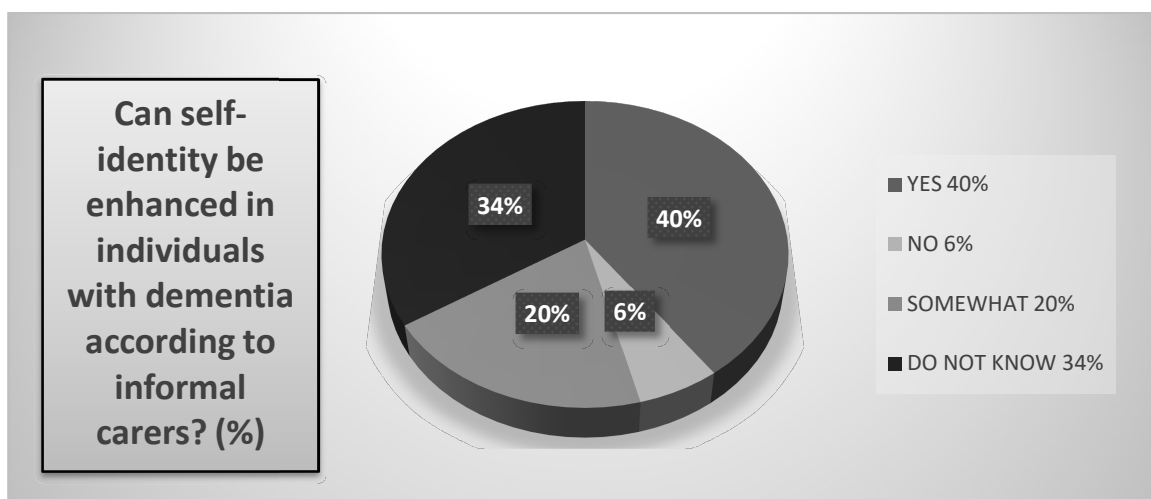
Figure 41 Percentage of informal carer responses regarding the potential enhancement of self-identity for informal carers

Summary of results from Figure 41:

<u>Informal carers</u>: Positive replies (40% for 'yes' and 20% for 'somewhat') from the informal carers stated that self-identity could be enhanced. However, 34% of informal carers 'did not know'. What is not clear is if this is their lack of

understanding of the concept or whether they didn't know if it could be enhanced or not. One informal carer stated that it could not be enhanced.

<u>Formal carers</u>: The Registered Nurses all replied positively, stating it would be possible to enhance the feelings of self-identity for those people with dementia (n=14) and the fifteenth stating 'somewhat'. These results indicate a clear lack of agreement between the formal and informal carers.

A further question from the Adapted-SIDQ (Questions related to self-identity, informal and formal carer, Q9) asked '*If enhancing the feeling of self-identity is possible, do you think it will contribute to the individual's sense of well-being?*'

Table 20 Informal and formal carer beliefs related to enhancing self-identity and impact on well-being.

Category of answer	Number and percentage of replies from informal carers		Number and percentage of replies from formal carers	
Yes, it will contribute very much	9	60%	14	93%
Yes, it will contribute somewhat	2	13.3%	0	0%
It will not make a difference	2	13.3%	0	0%
No it will cause harm	0	0 %	0	0%
No it will cause a lot of harm	0	0 %	0	0%
Do not know	2	13.3%	1	7%

Summary of results from Table 20:

<u>Informal carers</u>: The informal carers indicated that enhancing self-identity would 'contribute very much' to the well-being of individuals with dementia (n=9). Two participants felt that it would not make a difference to the well-being of those with dementia, but the questionnaire did not ask for participants to expand upon their answer. There were responses where informal carers did not know the answer, possibly from a lack of understanding about the concept of self-identity.

<u>Formal carers</u>: Formal carers gave positive responses to this question, with 93% stating that by enhancing self-identity it would 'contribute very much' to the individuals' well-being. Only one formal carer stated that they did not know.

Both formal and informal carers were asked (Questions related to self-identity, Q10) '*In which ways (such as certain activities, words or changing environment) could we in your opinion enhance or cultivate the self-identity feelings of this individual with dementia?*' Table 21 indicates the most and least important activities as indicated by formal and informal carers in enhancing self-identity in individuals with dementia.

Table 21 Activities which could enhance self-identity for individuals with dementia according to informal and formal carers

Enhancing activity	Informal Carer n =15	Formal Carer n = 15	Combined total from informal and formal carers
Listening to / playing music	4	5	9
Socialising / Friends	6	9	15
Watching movies / videos	1	3	4
Trips outside the hospital	6	10	16
Recalling memories / talking about past events	12	13	25
Cards, games or crossword puzzles	1	3	4
Talking about family or friends	10	11	21
Watching TV	1	1	2
Writing	0	2	2
Walking or exercise	3	4	7
Eating / tasting food	0	1	1
Spending time with/caring for pets	4	2	6
Religious activities	1	2	3
Discussion groups	2	5	7
Arts and crafts	0	1	1
Reading / studying	1	2	3
Discussing politics / current events	1	2	3
Bringing furnishings from home	1	1	2
Not relevant	0	1	1
Do not know	3	1	4
Other – Please specify	0	1	1

Summary of results from Table 21:

Informal carers: This group reported that 'recalling memories/talking about past events' (n=12) was the activity which could enhance self-identity in individuals with dementia the best, followed by 'talking about family or friends' (n=10) and 'trips outside the hospital' (n=6). Three of the informal carers stated that they did not know which activities would enhance self-identity.

Formal carers: This group reported that 'recalling memories/talking about past events' (n=13) was the activity which could enhance self-identity in individuals with dementia the best, followed by 'talking about family or friends' (n=11) and 'trips outside the hospital' (n=10). One formal carer stated that they did not know which activities would enhance self-identity, and one formal carer stated it was not relevant.

Both participant groups chose more than one option, with some participants choosing five or more activities or hobbies. From the combined total responses, participants felt that the most enhancing activities were 'recalling memories/talking about past events' (n=25), 'talking about family or friends' (n=21), 'trips outside the hospital' (n=16) and 'Socialising / Friends' (n=15).

'Listening to / playing music' was also an option chosen nine times, with 'walking or exercise' being opted for seven times, as was 'discussion groups'. The least enhancing activities were seen as 'bringing furnishings from home', 'arts and crafts' (n=1) and 'eating / tasting food' (n=1).

4.5 Free text responses from the Adapted Self-Identity in Dementia Questionnaire specific to self-identity in dementia

A free text response was included in two of the Adapted-SIDQ questions posed to informal and formal carers, but not to individuals with dementia.

4.5.1 Changes in identity

The Adapted-SIDQ asked (Questions related to self-identity, informal and formal carer, Q2) *'Does your relative/patient have any identities/occupations that are not based on/were of minor importance in his/her past?'* and *'When did these changes occur?'* (Questions related to self-identity, informal and formal carer, Q3) and '*If s/he had a change in identity what was your reaction to this change*?' (Questions related to self-identity, informal and formal carer, Q5).

Informal carers did not perceive any changes in self-identity (n=4) or during the course of their illness (n=5). However, the formal carers stated that there had been changes to many of the individuals with dementia's identity once their detailed documented history, discussions with family members, relatives and carers, and observations on the ward were considered.

One Registered Nurse commented that an individual with dementia (Participant 10) experienced personality changes as they had become more '*aggressive and angry*' in nature than before her illness, and another Registered Nurse stated that there was a change in a person's personality (Participant 7) but did not state how. Participant 13 had experienced a change in personality since their diagnosis; where previously they were warm and approachable in manner, throughout the illness they became aloof and preoccupied, expressing anger towards their family.

For the informal carers, responses related to identity change differed from the formal carers and their perception of identity change also differed. Relatives did note changes to aspects of identity; some almost immediately at the onset of the illness, another one to three years following diagnosis, and the last relative noted the change occurred four to six years post-diagnosis. The reaction to the changes in self-identity ranged from '*relieved*' to '*very painful*', with the majority of changes inducing negative emotions in the informal carers. The informal carer for Participant 1 stated '*he has changed, he talks and it sounds like the old him but when he talks he can't remember – I don't think he realises*'.

The informal carer for Participant 10 disclosed that the most important changes to his wife's identity were her poor memory and the development of a *'temper*'. He continued, stating '*staff may not yet have seen the anger/rage/hatred that my wife now experiences'.*

The son of Participant 11 stated '*little history of her past life has been taken and often not shared between carers* when asked if staff see his relative the same way with regards to her self-identity'.

4.5.1 Preservation of aspects of identity

The Adapted-SIDQ asked '*What identity does it seem that your relative/patient would like to preserve*?' (Questions related to self-identity, informal carer, Q13 and formal carer, Q4). Forty percent stated as a professional person, 33.3% stated as a part of a family, 13.3% as someone with achievements or unique traits, but 13.3% also stated they did not know.

4.6 Chapter Summary

Chapter Four has provided descriptive statistics to demonstrate the findings of the Adapted-SIDQ. Tabulated and graphical depiction provided information and summarised results related to the self-identity roles of those with dementia, and the importance of the self-identity dimensions from the Adapted-SIDQ. Cohen's kappa (κ) coefficient was used to measure inter-rater agreement between the three informant groups, to determine levels of agreement regarding what was important to those with dementia. Description was also provided of free text answers related to self-identity as provided by informal and formal carers.

Chapter Five will now discuss the meaning and implication of the results within contemporary evidence and practice, as well as the limitations and future research arising from this research.

Chapter Five – DISCUSSION OF THE STUDY FINDINGS

5.1 Research questions:

The aims of this research study were to answer the research questions;

> *(i)To what extent can dimensions of self-identity in individuals with dementia be ascertained when admitted to an acute psychiatric hospital for older adults using a culturally Adapted Self-Identity in Dementia Questionnaire?*

> *(ii) Is the culturally Adapted Self-Identity in Dementia Questionnaire an acceptable, practical and appropriate tool for use within the clinical assessment and care of individuals living with dementia?*

This chapter will provide an interpretation and evaluation of the significant findings from the Adapted-SIDQ, reviewed in context of the current literature and existing knowledge about measuring self-identity in dementia and dementia care.

A critical evaluation of the study will be presented, including the strengths and limitations of the adaptation process, its applicability and implementation, and the practicalities of the questionnaire as a potential research tool. Comparisons will be made between the research findings of the original paper by Cohen-Mansfield et al. (2000) and Caddell and Clare (2012a and 2012b), and this research study.

This chapter will discuss the contribution the study has made to understanding self-identity in people with dementia. In conclusion, there will be a review of the

clinical implications of this study and the importance of the findings for how we support people with dementia and future research in this area.

5.2 Key findings from the Adapted Self-Identity in Dementia Questionnaire

Novel aspects of the thesis will be discussed in detail, including; the success of implementing a research project within an acute psychiatric in patient ward for older adults living with dementia, the implementation of principles of co-production and inclusivity of individuals living with dementia in the research process and successful application of the Mental Capacity Act (Department of Health, 2005) to assess capacity to consent to inclusion in research activities of individuals living with dementia.

A summary of the key results from the study are provided below with detailed discussion on the points throughout the chapter:

- Individuals living with dementia, across the continuum of severity (from mild to the advanced stages of the illness) are able to complete the Adapted-SIDQ to reveal pertinent information regarding four dimensions of self-identity (job, occupational or professional role, family roles, hobbies and activities or personal achievements, attributes and traits).

- Multi-informant levels vary on the importance of self-identity roles including differences between time frames (past and present).

- The Adapted-SIDQ is an acceptable and practical clinical tool.

- The success of implementing a research project within an acute psychiatric in patient ward for older adults living with dementia.

- Implementation of principles of co-production and inclusivity of individuals living with dementia in the research process.

- Successful application of the Mental Capacity Act (Department of Health, 2005) to assess capacity to consent to inclusion in research activities of individuals living with dementia.

- There is an emphasis for Registered Nurses to develop informed, meaningful therapeutic relationships with their patients in order to provide a true reflection of person centred care.

- The Adapted-SIDQ tool provides relevant information on self-identify roles, but there are limitations with the questionnaire with regard to the depth and breadth of data collected.

5.3 First Key Finding: Completion of the Adapted Self-Identity in Dementia Questionnaire

Individuals with dementia were able to complete the Adapted-SIDQ. The Adapted-SIDQ was able to educe self-identity data from all participants across the informant groups, specific findings related to family role, gender-specific roles, hobbies and activities, and use of an individual's name.

Family roles - The husband or wife role was frequently reported as most important by those with dementia in both the past and present, and this finding was concurred across all informant groups. Personal achievements and traits linked to family relationships were most frequently chosen from the Adapted-SIDQ, particularly "d*evotion to family*". These findings reflect those of Cohen-Mansfield et al. (2000), Surr (2006) and Caddell and Clare (2012b), who identified quality of life

(for the individual living with dementia) is likely to be enhanced by positive social roles and perceived importance of family roles.

Others have explored the importance of the family relationships. Beard and Fox (2008) examined the relationship between family members and individuals when diagnosed with dementia. Respondents felt that their sense of self, their status and their family dynamics changed, but the significance of these relationships remained constant. Gillies and Johnston (2004) explored the family perspective of changes in identity and emotional isolation experienced as the individual's dementia progressed. The need for this was greatest when the individual with dementia was admitted into a formal care environment such as a hospital or care home where they felt that there was both physical separation and emotional distancing.

Since family members have a significant role in "*identity validation*" for those with dementia (MacRae, 2010, p.301), there is a need for healthcare professionals to reinforce past and present relationships to add to their sense of self, with positive family relationships providing attachment and a sense of belonging (Surr, 2006) reflecting psychological needs (inclusion, attachment and comfort) of those with dementia (Figure 1, Kitwood, 1997).

Gender-specific roles - Participants identified with strong occupational and professional roles, often gender specific.

All females conveyed a strong sense of self from being homemakers, a role adopted with high levels of importance, a positive attitude and pride in their familial history, including sharing experiences of devotion to family and success of family members was displayed. Lemme (1999) claims that identity is developed over time

surrounding certain themes, particularly families, and for these individuals their past experiences enabled them to stay connected both in the past and present. In this study, talking about their families appears to have contributed to the patients' identity roles as wives, mothers and grandmothers.

For male participants, family roles were also important, with most choosing the category "devotion to family" as either important or very important. However, "service to country" (three out of eight males), "birthplace" (two out of eight males) were also identified as important, as well as occupation, with all male participants identifying the importance of their previous job roles. One participant spoke about his past occupation as he previously worked within the grounds of the hospital, consistently using this as a conversation opener with staff and visitors to the ward during completion of his questionnaire. This important information was documented and explored with him. It appeared to enable him to hold onto a sense of agency, whereby he was able to initiate, execute and control his actions in the here and now by assigning significant meaning and their impact on his selfhood (Brooker, 2007). Through the structured format of completing this tool, there was an opportunity to support his sense of agency and provide continuity with important aspects of his identity as related to his previous profession.

Potential explanations for the results from this study relate to the traditional and cultural roles this cohort of individuals had in the United Kingdom. When this group of individuals were younger, particularly the 1950's, the image of a woman was most likely to have reflected a happy housewife who cooked the food, cleaned the house, and watched the children. Few women received a higher-level education and after school, many girls stayed home while their husbands worked to support the family, hence the varying levels of importance for each group and what was

important to them in the past and present. There is the potential for the results to be different in a younger cohort of individuals diagnosed with dementia, whereby more recent or current societal and cultural influences would have different impact on the roles women might have chosen, with more opportunities to gain, for example, further education, training and embarking on a career.

Hobbies and activities- Individuals with dementia reported interest in a wide range of hobbies and activities, with the most popular activities being gardening, reading or studying, watching television or films and socialising. These were fair to slight levels of agreement in those activities identified by the informal and formal carers with perceived positive attitudes towards their hobbies from informal carers and formal carers.

Meaningful occupation and activities are vital for health social inclusion and mental well-being to all age groups. NICE (2008) have suggested that they can be particularly beneficial for older persons to stay mentally and physically active.

Wang, Xua and Peib (2012) investigated leisure activities and cognition in people with dementia, identifying that activities can have a protective effect on well-being. Engagement in physical, religious or intellectual activities all had a positive impact on behavioural and psychological symptoms by lowering stress levels and increasing personal well-being. Yatczak (2011) states that participation in hobbies is a vital aspect of the non-pharmacological approaches to dementia care. Engagement in activities that are familiar, including using objects that the person with dementia has handled for many years helped to improve the mental well-being of those with dementia. Most significantly she claims that the ritual and repetitive nature of participating in hobbies and their familiarity provides comfort for

those with dementia especially in times of change or transition, such as being admitted to a hospital.

Self-identity and a person's name - The majority of individuals with dementia stated that they would like to be called by their first name, which was similarly agreed with by informal and formal carers. This indicates a growing acceptance of the use of first names, a move away from formal address with reciprocity of preferred name used between health and social care professionals and patients. Whilst assumptions are often made on name preference, it is now widely recognised that asking patients what they choose to be called conveys respect and overcomes barriers associated with a hierarchical and paternalistic relationship (Parsons, Hughes and Friedman, 2006).

Previous studies on name preference indicate a strong association between self-identity and name. According to Deluzain (1996), name, identity and society have commonalities; by giving a person a name, society confirms the individual's existence and acknowledges its responsibilities toward that person. A name differentiates an individual from others, representing their uniqueness as someone with needs and feelings different from those of other people. Draper, Wray and Burley (2013) explored the use of language specific to older adults; stressing name choice was not a neutral label, but a representation of identity. Brown and Draper (2003) claim that older persons are often addressed and spoken to in a patronising and disempowering manner, using endearments such as "sweetheart" or "mate", detracting from their individuality and self-identity (Kitwood 1997). In this study it was identified that it is a fundamental aspect of an individual's sense of self to be referred to by a preferred name, which was adhered to by most formal carers. This adherence by nursing staff reflects aspects of a person centred

approach being implemented within the acute psychiatric in-patient ward, contributing to the well-being of the individuals with dementia.

<u>Use of the Adapted-SIDQ with individuals living with mild to advanced severity of dementia</u>

In this study the Adapted-SIDQ was able to elicit responses from individuals with mild to severe cognitive impairment. The severity of cognitive impairment was measured using the Mini Mental State Examination (MMSE, Folstein et al., 1975), a well validated tool being used within health and social care, as well as research into dementia. This assessment focuses on five areas of cognition; orientation, registration, attention, recall and language. With a total score of 30, any score greater than 27 indicates "normal" cognition; whilst 24-26 indicates mild impairment, 18-23 moderate cognitive impairment, whilst scores below 17 indicates severe cognitive impairment.

Alternative quantitative methodologies for the measurement of self-identity in dementia identified in the previous literature search included the Twenty Statements Test, the Tennessee Self-Concept Scale (TSCS), and the Quality of Life-Alzheimer's Disease, (QoL-AD). Despite these tools being variate in their aims, measures and outcomes, nine of the twelve studies in the literature review using these three measurement tools used the MMSE to determine severity of dementia. The majority of these studies recruited individuals living with dementia with MMSE scores of 18 or over, representing participants with mild cognitive impairment and predominantly intact communication abilities. Two studies had MMSE ranges which included those with more severe impairments (Addis and Tippett, 2004, MMSE range 13-24, Cottrell and Hooker, 2005, with the MMSE

range 10-29) which falls within the "moderate" level. Only two studies used measures with individuals living with dementia across the complete range of severity of the illness from mild to severe forms; Eustache et al., (2013, MMSE range 5-23) and the SIDQ (Cohen-Mansfield et al., 2000) which used participants with a MMSE range of 0-22.

For this study, an MMSE was conducted with participants with dementia, which proved to be an effective indicator of cognitive impairment, yet the Adapted-SIDQ was still able to be used despite the high levels of cognitive impairment from the participants.

In isolation, the MMSE was unable to determine whether an individual had the mental capacity to consent to participate. One participant from this study had a MMSE score of four out of 30, however his capacity to consent to the study depended on numerous variables such as time of day and fluctuating levels of orientation. He was revisited several times to assess his capacity to participate in the study and on the fourth occasion he was able to consent. Pachet, Astner and Brown (2010) investigated the association between cognitive impairment as measured by the MMSE, and decision-making capacity, concluding that none of their participants were deemed to have capacity if their MMSE score was below 20. Using these criteria, seven of the participants in this study would have been excluded.

Over-reliance on the MMSE as an assessment of capacity potentially excludes numerous participants in a research arena which is already challenging to recruit into (Woodhall et al., 2010). This would also contravene the principles of the Mental Capacity Act (Department of Health, 2005) such as a presumption of

capacity and questions whether the individual has the capacity to make a specific decision at a specific time, not whether they have the ability to make decisions generally. The MMSE may not be an effective indicator in assessing an individual's capacity to consent to participate in a research study on a one off basis, rather it is an iterative process (Sherrat, Soteriou and Evans, 2007) and further exploration of consent to provide capacity is required through use of an individualised mental capacity assessment similar to that applied in this study, (Appendix 2), including further application of the strategies that were used to facilitate consent.

Throughout the study, individuals living with dementia were able to express their, feelings and experiences with regard to self-identity. However, they required support with the administration of the questionnaire, time taken, personal willingness and cognitive ability taken into account, the questionnaire could be administered and persons living with dementia provided answers related to their self-identity. Impairments in speech and communication meant extra time and support were provided to enable some individuals to use the correct descriptor or word to make these expressions.

Such responses adhered to Lemme's (1999) self-identity definition in that those with dementia maintained the ability to communicate the knowledge, feelings and attitudes that they hold about themselves as individuals. Matthews (2006, p.163) confirms this by stating that identity is "*an account of what it is to be the individual person one is, what makes one the same person at different times*".

This further emphasises the social constructionist premise that an "intact" self can be confirmed through the use of personal pronouns such as I, me, myself, mine and my (Sabat and Harre, 1992).

An implied loss of identity originates from research into autobiographical memory, such as that of Addis and Tippett (2004) who explored the retention of memory in individuals living with dementia at home, within residential homes or living independently in the community. They used the Autobiographical Memory Interview, Autobiographical Fluency Task, Tennessee Self-Concept Scale and Twenty Statements Test and concluded that people with dementia had a "weaker" or more vague sense of self-identity.

These claims were not upheld from the Adapted-SIDQ results, which indicated aspects of preserved sense of self, in some cases, severity of cognitive impairment, and those living with dementia were able to identify these aspects of preserved self. Whether this represents core aspects of identity, all or some dimensions, is not known. Lesser (2006) emphasised there are no philosophical grounds for asserting that identity is destroyed within dementia, and explored retention of identity through the progression of the illness. This research has confirmed that through identifying a suitable tool by which those living with dementia are able to express aspects of their self it suggests some preserved state of identity. The Adapted-SIDQ resulted in aspects of preserved sense of self being revealed but whether this is a weaker/more vague than that obtained with other tools and what, if any reflects the core structure of self-identity, more research is required to define the quality of self-identify revealed.

5.4 Second Key Finding: Extent of informant agreement

The second key finding was there were substantial differences between the three informant groups across dimensions in both past and present time frames.

Across the four self-identity dimensions of the Adapted-SIDQ, the level of agreement was never higher than that of "moderate" according to the kappa (k) value descriptors of Landis and Koch (1977).

<u>Agreement between individuals with dementia and informal carers</u>

It was anticipated there would be a high level of agreement between the informal carers and those with dementia. However, it was evident that the informal carers in this study did not always appear to know the preferences of their relative with dementia across the four self-identity dimensions either in the past and present.

The agreement levels for occupation role were "slight" in the past and "slight" in the present, for family role, there was no level of agreement in the past increasing to "moderate" in the present, for hobbies and activities there was no agreement in the past and this increased to "fair" in the present. For personal attributes, the highest level across all four self-identity dimensions and time frames was recorded with a "fair" level for agreement in the past, but this agreement level increased to "moderate" in the present. However, there was also a high level of agreement related to what the individual with dementia preferred to be called, with all fifteen participants from the informal carer groups and fifteen individuals with dementia having a consensus of opinion of choice of name.

A number of factors could account for the lower levels of agreement, such as changed preferences over time, reduced strength of feeling or level of importance due to the illness, or unknown influences.

Agreement between individuals with dementia and formal carers

The levels of agreement between those living with dementia and their formal carers were explored within the present time frame, as the formal carer would not have sufficient information related to the individuals past to effectively measure. Overall, there were no consistent levels of agreement across the four self-identity dimensions. There was a "slight" agreement level for occupational role, for family role, the level of agreement was also "slight", for hobbies and activities this was no level of agreement and for personal attributes, a "slight" level of agreement was recorded. There was a reduced level of agreement related to what the individual with dementia preferred to be called, with fourteen participants from the formal carer groups and fourteen individuals with dementia having a consensus of opinion of choice of name. One formal carer assumed that an individual with dementia would prefer to be called by a nickname, which was not the case.

A prerequisite of person centred care is the ability to describe preferences, needs and interests of those with dementia, but across the four self-identity dimensions, the Registered Nurses did not have higher than a "slight" or "fair" level of agreement with the individuals with dementia. This reflects findings from Nowell et al. (2011) where patients with dementia reported differences between what they deemed was important and what was considered of importance by eliciting the nursing staff's opinion.

In this research study, it had been decided that Registered Nurses would complete the Adapted-SIDQ and not Health Care Support Workers (HCSW) who, instead, adopted a supportive role if the patient became distressed throughout consent and data collection processes. This decision was based upon my previous clinical experience, as a Registered Nurse on an acute psychiatric in-patient ward, but also as a lead nurse in this particular care environment, and knowledge related to the contribution Registered Nurses have to ensuring the delivery of person centred care.

One potential explanation for this lack of agreement between the person living with dementia and the formal carer is that the Registered Nurses did not always know the personal preferences, or background of patients, possibly due to their intermittent contact and multifunctional role in shift management. With hindsight, it is possible that the HCSW might have been better informed to complete the Adapted-SIDQ since, currently, in the environment the research took place; they have higher levels of direct patient contact time. It is feasible, therefore, that HSCW rather than Registered Nurses have more knowledge and personal awareness of patient preference. This is beyond the remit of this study, but is a factor to consider as to who is best placed, within the multi-disciplinary team, to complete the formal carer questionnaire.

The Adapted-SIDQ effectively measured the strength of self-identity roles through determining the relative importance of each self-identity dimension in the present time frames. Individuals with dementia were able to articulate this strength by indicating what was important to them in the past and the present. Informal and formal carers also indicated what was important to those with dementia regarding job and family roles, hobbies and activities and personal attributes.

These results questioned whether therapeutic interventions for those with dementia should be based upon past experiences or focus instead on current knowledge and experience of the "here and now". The Adapted-SIDQ appears to be a useful tool in eliciting from the individual with dementia aspects of self-identify which has preserved strong links with the past, as well as aspects of their current life which are important, or more important to them in the present. This information could be used to plan and focus individualised non-pharmacological therapeutic pathways, either reminiscence approaches (reminding them of facts about themselves and their current environment using materials and activities) or validation methods (exploring the past and how this relates to the way they are feeling now) to maintain their self-identity.

It was not possible to compare these results to additional studies that have used the SIDQ due to lack of methods being published. Cohen-Mansfield et al. (2000, p. 390) describe the "*agreement rate*" and "*correlations*" but do not state the statistical test used, and measurement of agreement was not included in the Caddell and Clare (2012a) paper as multi-informant comparisons were not employed.

5.5 Third Key Finding: Acceptability of the Adapted Self-Identity in Dementia Questionnaire as a research and clinical tool

The Adapted-SIDQ required multi-source data from each participant group in order to facilitate analysis. Cohen-Mansfield et al. (2000, p.383) justified this approach stating, 'because *many persons with advanced dementia are unable to communicate, their sense of identity has to be investigated through informant*

reports. In this study, we aimed to query both the elderly person who is suffering from dementia, their formal caregivers, and their informal caregivers'

This approach reflects the ideals of partnership working as outlined in the Royal College of Nursing 'Triangle of Care' (2013) and my own values and beliefs related to patient and carer involvement. Within dementia care a great deal of information can be obtained, which can be used for the benefit of the patient and care outcomes.

However, this approach is not without its difficulties. According to Holmbeck, Li, Schurman, Friedman and Coakley (2002) this strategy has intrinsic limitations when used within the research arena, such as time delays, and due to its resource-intensive design it can induce delays in recruitment and data collection, as was encountered in this study.

It appears that all participants understood the multi-informant nature of the research as explained in the study invitation letters and consent processes. This approach recognises that each participant has a valuable contribution to make within the research process, reflecting the inclusive and participatory principles as outlined in the Triangle of Care (RCN, 2013).

In summary, the value of multi-informant approaches lies in capturing the unique perspectives held by each participant, giving the potential to draw conclusions from a variety of sources for improved research outcomes.

Individuals with dementia - All fifteen individuals with dementia, (whether with mild, moderate or advanced dementia symptoms) with support were able to complete the Adapted-SIDQ. Although not explicitly asked of this cohort of people, it

appears that, if completion reflects acceptance all fifteen questionnaires were completed. However, the majority of questionnaires were completed with varying forms of support from myself, which included; assessment of physical and sensory impairments and making individualised adjustments according to ability, reading information to the individual, using the pictorial options for paperwork, flexible one to one time so no pressure was induced in answering the questions, a quiet environment, revisiting on different occasions and the relatives awareness or presence throughout the completion of the questionnaire. However, assisted completion of the questionnaire within the clinical setting may adversely impact on the usefulness of the questionnaire due to the time needed to train those administering the tool and time needed to complete it.

Informal carers - Fifteen informal carers who participated in the study completed the questionnaire in full as instructed, with no data fields left blank, suggesting that there was an acceptance associated with its use

However, 12 informal carers voiced difficulties with the suitability of the questionnaire prior to consenting to participate, volunteering explanations as to the challenges associated with the timing of administration of the questionnaire, its length, its, relevance and the potential impact the study would have on their relative with dementia and declined to participate.

Formal carers - Six Registered Nurses from Ward A and C consented to take part in the study. These were the same six registered nurses involved in the adaptation of the SIDQ (Phase One of the study) who contributing to its refinement and adaptation. Concerns regarding data collection were identified early, providing opportunities to problem solve with the nursing team. Patel, Doku and Tennakoon

(2003) claim that by reviewing a study design with the clinical team, gaining their views, and working collaboratively, barriers can be overcome, therefore facilitating the research process and subsequent data collection.

Anecdotal feedback from this cohort suggested that as a one-off questionnaire for each occasion, it was quick and easy to administer and that gathering this information had provided more insight into their patient's needs and subsequent care planning. However, there were some reservations voiced. Most Registered Nurses considered the Adapted-SIDQ a "tick box" exercise, too formalised, process driven and provided limited superficial information, which was not detailed. They proposed that the questionnaire needed a more personalised approach, incorporating free text replies, less of a repetitive nature across the four self-identity domains, the inclusion of more self-identity domains to include more emphasis on personality traits (for example benevolence, extroversion, or decisiveness) or personal preferences, likes and dislikes and questions to try and understand the person as an individual.

Completed questionnaires from the Registered Nurses were submitted within the time frames requested despite the study setting being a challenging psychiatric in-patient assessment ward. There were no incomplete domains within the questionnaires and all fields provided data as instructed. The demands and constraints on a Registered Nurse's time are immense, with a balancing act between implementation of clinical care, admissions and discharges, medication rounds and multi-disciplinary reviews. The inconvenience of completing the Adapted-SIDQ, within the two week time period, added to the pressure that the nurses encountered. In addition, if a Registered Nurse was a "Named Nurse" to more than one patient involved in the study, they were required to complete the

Adapted-SIDQ for each patient on their caseload. However, the detrimental impact on nurse's time was minimised by incorporating data from the completed Adapted-SIDQ into the clinical assessment and treatment plans for the individuals with dementia.

5.6 The success of implementing a research project within an acute psychiatric in patient ward for older adults living with dementia.

As part of the background to this study, I highlighted that research studies from the past 10-12 years based within acute old age psychiatry in-patient wards have focussed on; the acute general hospital setting on those living with dementia (Bridges et al., 2010), effectiveness of acute psychiatric treatment (Draper and Low, 2005), discharge processes and destination of discharge related to patient outcomes for those living with BPSD (Bucher et al., 2016 and Tucker et al., 2017), or staff perceptions of seclusion and restraint (Muir-Cochrane et al., 2015) and patient aggression, (McCann et al., 2015).

There appears to be a scarcity of research within acute in-patient psychiatric wards that care for older adults living with dementia. One service improvement report was found, conducted by Stamp, Dickinson and Humphrey (2012) which investigated improving the patient experience of admission to an Older Persons Acute Mental Health Ward with the aim of promoting partnership working between patients, family, carers and the nursing team. However, the report did not include the experiences of those living with mental illness within that care environment and no explanation for this lack of involvement was provided.

Reflecting on this lack of research activity within acute psychiatric environments, possible explanations have been identified;

(1) <u>Lack of understanding of the environment</u> - Historically psychiatric hospitals have held an air of obscurity, with many of the negative perceptions of "asylums" with their prison-like, punitive approaches being perpetuated through media. Patients who are aware of the name of the local psychiatric hospital communicate dismay and distress when they know they are to be admitted, and families and carers are still under the impression there will be bars on the windows of the wards (Bedell, 2002). Within the research community these impressions will be much less, but there is still a prevailing air of secrecy within psychiatric care which is acting as a barrier to the advancement of research and evidence based care within mental health nursing.

(2) <u>Perception of the complexity of patients with mental illness</u> - As with the literature review, it was highlighted that much of the research into dementia care tends to involve those with MMSE scores of 18 or higher where individuals maintain cognitive and communication skills. Within the acute setting, an individual's cognitive functioning fluctuates greatly with many factors contributing to this including; progression or severity of the illness, behavioural and psychological symptoms, or psychopharmacological or non-pharmacological interventions. In addition to the individuals mental health needs, there were also physical, sensory and impairments to take into consideration. Being a mental health nurse working with older adults provided fundamental insights required as to the needs of this care group, which facilitated their participation and reduced the perceived barriers related to their complex health needs (Rahman and Harrison-Dening, 2016).

(3) Access to the research site - Obtaining access to acute psychiatric services may pose a challenge for researchers, often knowing who to contact as an initial point of discussions is a mine field. This barrier may prevent researchers from progressing their projects. NHS R&D offices can offer advice and support on the set-up of a research project at their organisation, including information on local arrangements for support services relevant to the project. These support services may include clinical supervisors, line managers, service managers, support department managers, pharmacy, data protection officers or finance managers depending on the nature of the research

I understood that the research project was significantly beyond the current scope of research into the field, but I strongly felt that it was obtainable, with the driver of improving the care for my patients. Being immersed within the culture of acute psychiatry for older adults throughout my career, these areas were not perceived as a barrier to the research but more facilitator. I understood the potential challenges and knew there were gaps in knowledge specific to the acute hospital assessment of self-identity in those with dementia. I used clinical knowledge, leadership skills and creativity to be able to manage the research problem and implement the research process to answer the questions posed.

5.7 Implementation of principles of co-production and inclusivity of individuals living with dementia in the research process.

Within Cohen-Mansfield et al.'s (2000) original exploratory study, the Self Identity in Dementia Questionnaire was designed in several stages. The preliminary stage involved a "committee of psychogeriatric experts"(Cohen-Mansfield et al., 2000, p. 384) and despite the published paper not stating who these people were, it was

these 'specialists' who drew together the major variables and themes that then went on to construct the completed questionnaire.

Christie (2007) states that when people are diagnosed with dementia they often experience 'prescribed disengagement'. This is the way many professionals assume that people with dementia will 'fade away' from the public consciousness. They often find themselves waiting on others to include them, being excluded, stigmatised and isolated and I wanted to give them a "voice" within my study.

When I was in the planning stages of this study, I knew I wanted to adopt a participatory design whereby those living with dementia were able to actively contribute to the process. Drawing upon my core nursing values and principles, namely honesty, trust, establishing and building rapport and relationships, communicating in its many forms, being supportive and understanding, as well as being patient and persistent, that inclusionary ideal was achieved.

Strategies to overcome the challenges encountered included trying to understand what works best for the individual living with dementia. For this to be successful I again needed to draw on my nursing knowledge and skills. My experience of working with older adults with dementia, having the knowledge about the illness and symptoms those present, acknowledging abilities without focussing on impairments, yet using strategies to overcome them, all facilitated the inclusionary process.

Further challenges addressed to ensure that a participatory approach was implemented were effectively managing time; my time as a clinician and

researcher, the time of my nurses, awareness of the time requirement to complete the questionnaire for both the informal and formal carers. My co-production associates living with dementia had a variety of impairments, but through recognising their abilities and to empower them to work at their own pace was vital for the success of this aspect of my study. It did mean that any achievements did take longer to establish but the feedback was so insightful and made a huge contribution to the redesign of the questionnaire.

Lastly, reflecting on the consultation and co-design processes, I needed to ensure I was not merely being tokenistic – this was so important to me. Support from a clinical supervisor at the time reassured me that this was not the case, and I was achieving what I had set out to do. There needed to be a commitment and understanding from all involved, which is where my support and leadership role came to the fore. Involving those living with dementia and their carers in the research process not only advanced my learning and insight to many aspects of dementia, but it ensures that all those involved are provided a sense of purpose, worth, and enablement.

A fabulous mantra adopted by the Alzheimer's Society is '*Nothing for us, without us'* which needs to be adopted for all aspects of life for those living with dementia.

5.8 Successful application of the Mental Capacity Act (Department of Health, 2005) to assess capacity to consent to inclusion in research activities of individuals living with dementia.

Research is crucial to advancing knowledge about dementia, yet the burden of the illness currently outpaces research activity, which has led to a '*dearth of evidence*

for this population' (Prusaczyk, Cherney and Carpenter, 2017, p. 63). Throughout much of the literature included in the review of self-identity and dementia, there was mention of consent by proxy (Tappen et al, 1999), assent was sought from carers or staff caring for those with dementia, or the ethical processes were not highlighted (Fazio and Mitchell, 2008). However, newer studies such as that by Jetten et al. (2012) did adhere to the principles as outlined in the Mental Capacity Act (MCA, Department of Health 2005) and discussed the processes used for those potential participants who many lack capacity to consent.

The Mental Capacity Act (Department of Health, 2005) ensures that those people who lack the capacity to make decisions for themselves have a statutory framework to support, guide and protect them. It outlines who can make decisions, in what circumstances and how to do this is. The MCA (Department of Health, 2005) acknowledges the importance of research activities for those who lack capacity or encounter illnesses where capacity either fluctuates or is lost. It is Sections 30 - 34 of the MCA (Department of Health, 2005) that focus on research involving those individuals who potentially lack the capacity to consent to participate.

Following this Act, guidance was published by the British Psychological Society (2008) and the Medical Research Council Ethics Guide (MRC, 2007) which aimed to support researchers to involve those participants who either lacked capacity to consent in research activities or whilst capacity to consent partway through the research process.

The MRC has provided guidance for researchers conducting studies involving those who potentially lack the capacity to consent since 1991 to ensure that such

research is conducted ethically and is sensitive to the needs of the individuals involved. The 2007 MRC publication covers general principles and specific principles of the Act with regard to research activities, risks and benefits, capacity, competence and consent and the legal framework within which such research can be carried out, yet, it is only within the past 5-10 years that research involving those with dementia who have adhered to the MCA is being published.

The National Research Ethics Service (NRES) ensured that the potential participants in this study would be safeguarded due to their vulnerability. They appear to have moved away from dissuading researchers and attempt to engage cognitively impaired individuals whose capacity to consent may be questioned, rather they are encouraging and facilitating processes for this population to be included in research studies.

Unfortunately I found that the MRC (2007), the British Psychological Society (2008) and NRES were not forthcoming in providing realistic and practical terms in the 'how' to implement ethically sound research with those with dementia. Their guidance was comprehensive in adhering to ethical principles, yet they lacked the clinical 'real time' aspects of implementing aspects the Act within a challenging research setting.

Mitty (2012) states that there is no 'gold standard' for determining capacity within research activities, yet I sincerely believe that a high standard of ethical principles were adhered to and successfully implemented throughout this research study. Factors which facilitated this achievement included; mental health nursing skills, using nursing experience from clinical practice to develop personalised capacity

based assessment paperwork and using a variety of creative means to positively engage potential participants.

Reviewing the literature included within this study on self-identity and dementia there was not only a lack of nurse participation, but a real lack of mental health nurses either leading or participating research activities was disappointing. There are many skills mental health nurses possess which are attuned to what is required to ensure ethical principles are adhered to within research. These include excellent observation skills, communication and listening skills, the ability to gain a patient's trust, empathy and the ability to relate to people, the ability to stay calm in difficult or challenging situations and an assertiveness and ability to advocate for patients. My knowledge and skill as a nurse ensured I embedded the principles of the MCA (Department of Health, 2005) not only into my clinical practice, but then adapting that knowledge and experience into my research study. When compared to the Cohen-Mansfield et al. (2000) study where research assistants were used to engage the potential participants, it can be questioned that the lack of success in their recruitment originated from the lack of engagement skills as noted above.

Using the MCA (Department of Health, 2005) Two Stage Assessment of Capacity (Figure 4), I met the needs of this research study in that I was able to determine if the individual had an impairment of mind and whether they were sufficiently impaired to make the decision related to consenting to participate in my research project. I needed to develop my own paperwork to document my assessment and findings, which met the requirements as demanded by NRES, but also adherence to ethical principles to protect vulnerable participants. However, I do believe that there is a need for more evidence based decisional capacity assessment tools for use not just within clinical practice but also within research activities.

Facilitating processes implemented to support people living with dementia through the capacity assessment and consent seeking procedures were creative, innovative and wide ranging.

Time, often a precious commodity within a busy psychiatric ward, was one of the most important factors in supporting people to be able to give informed consent. Taking the time to revisit an individual on two, three or four occasions should not be a distracting factor; if anything it should provide the impetus for that individual to feel worthy and empowered to participate. However, if I was able to analyse the cost effectiveness of my time (and that of my Registered Nurses) as a resource against utilising a clinical researcher within the study, it would have been interesting to establish if the results would have been the same, if the same level of recruitment was achieved or the length of time for recruitment to gather the required minimum data for the feasibility study.

Assisting the individuals with dementia to understand the research study was a challenge with some patients. Factors which facilitated this process included: knowing the patient, taking into account any physical and sensory limitations, using a variety of formats of information; spoken, written or visual images. All needed to be considered as a facilitating measure to aid understanding. Enabling the patients to weigh up risks associated with the study required the afore mentioned strategies to be implemented. Throughout the NRES process I had considered all the potential risks that may be encountered for vulnerable participants and none were identified bar potential distress at being questioned. These risks were to be mitigated by support staff on the ward. However, explaining this to the potential participants and that they could withdraw at any time required use of pictorial paperwork (Appendix 2).

For the individuals to communicate their agreement or refusal to participate was one of the less challenging aspects of the consent process as many of the patients living with dementia were keen to spend one to one time with me to explore their past and present lives, but I needed to ensure that the ethical aspects of the study were adhered to in that they understood its aims, weighed up any risks and the agreed to participate based upon the information I had provided.

This research project has demonstrated effectiveness in various strategies for involving and recruiting people with dementia in research. Those with impaired capacity had access to appropriate support systems including experienced mental health nurses to help them make decisions that affect their lives and that of others.

Recently published papers (Murray, 2013, Ries, Thompson and Lowe, 2017) and Prusaczyk et al., 2017) acknowledge these challenges and the need for reform to embrace an inclusionary approach for those with dementia, and recognise the need to celebrate all opportunities to move away from the dearth of evidence based care to improve the well-being of those living with dementia.

5.9 Study results pertinent to the nursing profession

The notion of comprehensive or holistic care for a patient includes not only medical and physical health needs, but psychological and humanistic needs, social background and personal identity. As a consequence of this research, it clearly identified that the Registered Nurses did not know the patients under their direct care within their role as Named Nurse. It has identified a quest for quality

and efficient care within the acute psychiatric in patient ward, which would contribute to the creation of a sustainable and innovative environment where staff could function at their highest potential and adding value to our service and the outcome for the patients.

Translating this research into practice, as a leader within the nursing profession, I saw this as a critical reflection of my leadership within the ward; what were the core values of the Registered Nurses within my team that they did not have an awareness of who their patents were? Did my nurses have a basic working knowledge, or knowledge regarding aspects of their patients lives? Did different grade of nurse have an impact on the knowledge learned about their patients? What were the barriers which potentially led to such a low level of awareness from the Registered Nurses and how could they be overcome? There was a real concern that if the nurses did not know the patients under their care, or lacked knowledge related to important aspect of their illness; it was a safety risk, not only for the patient, the individual nurse and also the whole team on duty. Through clinical supervision I was able to explore these questions and the associated feelings experienced, being able to resolve the negative aspects identified, to view them as a positive opportunity to improve practice through an action focus.

Transformational leadership transforms people and organisations to change their perceptions. I felt responsible to enlarge the vision and insight from the research and share my new understanding clarify purpose and bring about change which is based within the person centred philosophy, permanent, self-perpetuating and momentum building.

The relevance of person centred care to modern day nursing is well documented and is central to several policy documents associated with older adults, dementia and dementia care, including the National Institute of Clinical Excellence (NICE) guidance on Dementia (Department of Health, 2006, updated 2016), the National Dementia Strategy (Department of Health, 2009a), Dignity Challenge (Department of Health, 2009c) and The Dementia Challenge (Department of Health, 2012) and there is a consensus that person-centred care equates with quality care (Innes, Macpherson and McCabe, 2006,

However, the term 'person centred care' is often used without a true reflection of what the philosophy means.

Organisational support is vital for person centred care to be achieved. All too often there are bureaucratic barriers that need to be overcome such increased management and budget-led services. Quality improvement initiatives that release time to care and practice development associated with person-centred cultures (McCormack, Manley and Walsh, 2008) are a means by which services can review their organisational philosophy and whether person centred care is being achieved.

Yet we may question whether the person centred approach is an ideal that is not within our reach. As clinicians facing increasing standards, pressures, expectations and service changes with an emphases to deliver safe, effective caring and quality driven care, is this achievable?

Over the past year there has been much media interest in the challenges front line nursing staff are facing in day to day clinical practice and whether delivering the essentials of nursing are feasible within challenging environment. With low morale

within the profession nationally, it appears a huge hurdle to overcome in order to achieve the best outcome of our patients.

On a more strategic level, nurses often practice across a continuum of healthcare settings and bring a voice to the work of nursing, for example from this study I was able to articulate and raise awareness to colleagues within the University and within several arenas when disseminating the outcomes of the study what modern day mental health nursing for those living with dementia involves.

Visioning and futuristic thinking on how to emphasise the importance of a nurse/patient relationship within clinical practice will influence a transformation of new knowledge, skills and abilities focussing on relationship base care to achieve a balance between safe and quality healthcare.

Leadership by nurses at all levels in the organisation and all stages of their careers is more important now than ever in light of the Francis Report. We all face unprecedented changes in society and in the expectations of the public that will challenge everyone and shape services in future. These changes need to have an evidence based focus on quality of standards for safety, effectiveness and patient experience and the delivery of compassionate care for those living with dementia. The true extent of the impact of the nurses not knowing their patients is well beyond the scope of this study, but it has identified that there was a definite need for further research within this area.

In summary, strengths of the approaches used and the Adapted-SIDQ include;

- Research studies can be implemented within the acute psychiatric in-patient environment including individuals with dementia, where the

literature suggests there appears to be a dearth of research due to the real or perceived challenges imagined.

- It was feasible to use the Mental Capacity Act (Department of Health 2005) to provide an ethically sound research study involving individuals living with dementia.

- There are a wide variety of creative and innovative methods to engage those living with dementia, determine capacity and consent to inclusion within research studies.

- The experience, expertise, knowledge and skills within the nursing profession facilitate the research process

- Through using the Adapted-SIDQ, it is feasible to establish aspects of self-identity in those living with dementia.

- It is a tool that can be used across the continuum of dementia from mild to severe stages.

- The Adapted-SIDQ appears to be an acceptable questionnaire to individuals living with dementia, their informal carers, relatives and formal carers. The Adapted-SIDQ is an easy, effective tool to use and has the potential for use as a standalone method to elicit self-identity information without the need for a multi-informant perspective.

The tool appears to be both practical and useful as a research tool with potential to inform clinical care.

5.10 Fourth Key Finding: What the Adapted Self-Identity in Dementia Questionnaire does not provide

Non-pharmacological interventions based on the life experiences of those with dementia have been demonstrated to have a positive effect on mood, behaviour and well-being (Cohen Mansfield et al., 2006). The Adapted-SIDQ was able to elicit the self-identity dimensions, as defined by this tool, of those living with dementia. It provided a vehicle for obtaining background information and determining what was important to them in the past and present upon which non-pharmacological interventions can be based. The questionnaire can be compared to other formats used to collect and elicit self-identity information from individuals with dementia and/or their carer.

The Adapted-SIDQ does not provide the depth alternative which other available tools provide, such as life history work or the "This is Me" document (Alzheimer's Society, 2015b). Life history work is a method involving "*a person and/or their family to find out about their life, recording that information in some way and then using the information with the person in their care*" (McKeown, Clarke and Repper, 2006, p.237). Benefits of this work include understanding the individual, improving care for the person with dementia (Gibson and Carson, 2010) and improvements in the quality of relationship between the relative, person with dementia and formal carers (Subramaniam, Woods and Whitaker, 2014), with its credibility well documented (National Dementia Strategy, Department of Health, 2009a).

Formats of life history work include a question and answer sheet, questionnaires, photograph books, and scrap books or albums. A life story book has no structured format, but may include a timeline, along which important or significant life events

linked to self-identity dimensions can be placed. It can be developed at any stage of the illness, may or may not require support from another person to create, and once completed can be repeatedly used as the dementia progresses. It is something that is for the individual with dementia to share - they have ownership of the book, which is an important aspect of maintaining control within their care. It is able to include visual, sensory or tactile cues to stimulate those with cognitive impairment. Of particular note is the inclusion of photographs or mementos which are used to help stimulate and maintain memories and aspects of self-identity. It is easily accessible by those involved in the care partnership and they can simply be transferred with the person with dementia if needed.

In comparison, the Adapted-SIDQ is a once-only administered questionnaire. It can be used as part of a multi-informant approach or for single person only completion and the findings from this study suggest it can be completed by persons at different stages of dementia progression providing sufficient support is available. Depending upon when the Adapted-SIDQ is completed it can be done independently as a questionnaire or with support, as a framework for informal conversations.

The Adapted-SIDQ in its current questionnaire format could be transferred with the person with dementia as they are discharged from the psychiatric in-patient care environment to a residential or nursing home. However, the new care provider may not acknowledge its clinical significance and there is an identified need for an explanation to understand its uses, with a complete multi-disciplinary handover as to the effective use of the self-identity information, compared to life story books which are self-explanatory.

The ownership of the data collected through completion of the Adapted-SIDQ is firmly with the individual collecting the data and how they use it, rather than the individual with dementia having control over the information it contains. In addition, in the present format, it is not able to include visually stimulating cues or photographs to aid reminiscence and enhance selfhood as with life history books.

The Adapted-SIDQ in its current questionnaire format was restricted in that it was not able to expand to include free text to obtain vital information in addition to the four self-identity areas. However, if a revised format of the questionnaire is validated, additional information about the person could be collected in the Adapted-SIDQ format using the "comments" sections which could reflect aspects of life history work (Appendix 3).

5.11 Demand and integration of the Adapted Self-Identity in Dementia Questionnaire as a clinical tool

As previously stated, there is a recognised demand for a tool or measure to capture aspects of self-identity, such as the Adapted-SIDQ, within the clinical environment from health and social care professionals. This is, reflected in relevant policy documents stating how the use of such tools are related to high quality care for older adults with dementia (SCIE, 2013). There is currently no formal measure of aspects of the patient's self-identity included in the assessment process of those with dementia on the acute psychiatric in-patient ward.

As this was a study to determine the feasibility of the tool, it was not within its remit to fully evaluate the integration of the Adapted-SIDQ into the clinical environment.

However, the Registered Nurses were able to use the Adapted-SIDQ within the care environment successfully as they were able to complete the questionnaires as required and use the knowledge gained to inform care interventions for those with dementia. However, the ward uses electronic health records (EHR) with many of the assessment tools based within the computer system. No prior consideration was given to using an electronic resource such as a tablet or a computer-based version of the Adapted-SIDQ, but in order to ensure sustainability to using the Adapted-SIDQ in future, it is a possibility to review how this could be achieved with an IT system.

The use of the Adapted-SIDQ corresponds with the organisational goals and culture in working in partnership with patients and their carers to deliver better patient outcomes. It could easily be integrated into the systems in place on the ward, and as the nurses were receptive to be involved in the feasibility study, it could be inferred that they would be just as motivated to invest in its full integration into the culture of care and treatment delivery on the ward. The Adapted-SIDQ was deemed to be successfully integrated for the duration of the study, and bar further considerations, such as being integrated into the current nursing assessment systems for use within the acute psychiatric in-patient environment, its present adapted format would have to be addressed. It would need to be included on the admission checklist for documentation to be completed as soon as possible on admission to use the data in care planning, as well as being incorporated into the EHR system that is currently in use.

A further challenge to the implementation of the Adapted-SIDQ as a clinical tool is the need to determine permissions for its use. The original SIDQ was sent to me by a colleague of Dr Cohen-Mansfield, Dr Thein, in 2010 with the copyright status

of the questionnaire at the bottom of the questionnaire stating "© Jiska Cohen-Mansfield, 2003". The tool was free to use, but is not in the public domain, with access to the original papers only through the original research team. Therefore, further discussions with Dr Cohen-Mansfield would be crucial prior to any further modification of the tool for clinical use.

5.12 Limitations of the study

This feasibility study aimed to establish whether a cultural adaptation of the original SIDQ was appropriate to a different country, new clinical area or different population, yet limitations of the study were encountered, including questionnaire length, non-participation in the study, length of recruitment phase, inclusion and exclusion criteria, questionnaire delivery, and choice of only one study site.

5.12.1 Questionnaire design and delivery

Despite extensive piloting, the length and lay out of the questionnaire did not encourage the informal carers to be engaged or included. On reflection, further consultation and testing with the informal carers in the final stages of adaptation of the tool may have contributed to overcoming this limitation.

A clear, concise design is fundamental in health service research involving questionnaires (McColl et al., 2001). Working with representative stakeholder groups, the Adapted-SIDQ was co-designed following feedback on layout, styling and language. Literature was reviewed to ensure that the layout, styling and language was user-friendly, and issues identified through the stakeholder consultations were addressed.

Clarity was required in the questionnaire covering letter, but it was later identified that the return instructions were not clear. No self-addressed envelope was included in the recruitment pack, nor was a suggested return date provided. Prior consideration to these three factors may have reduced potential ambiguity and facilitated improved participant response rates for the study.

Inclusion and exclusion criteria - Throughout the study informal carers were all family members, with no informal carer being a friend or neighbour adopting the role. The questionnaire is "family-centric" in this respect, and did not reflect the potential for diverse family units within the United Kingdom (for example, single parenthood, cohabitation, gay, lesbian, bisexual, and transgender (GLBT) relationships, or singlehood). The original Adapted-SIDQ did not stipulate a traditional family unit; it asked those with dementia who was most important in their family, which could accommodate diverse answers, if the individuals felt able or willing to disclose such. Participants with no informal carers were excluded from the study due to its multi-informant design, but only for data analysis purposes, the questionnaire information could still be used to inform care planning.

HCSW role and involvement – The HCSW adopted a supportive role if the patient became distressed throughout consent and data collection processes when the questionnaires were being completed. On reflection, the HCSW might be better informed to complete the Adapted-SIDQ rather than the Registered Nurses since, currently, in the environment the research took place; they have higher levels of direct patient contact time. This would be easily implemented, with the potential for higher levels of agreement between this carer group and those individuals living with dementia, as well as recognising what is important related to their self-identity.

5.12.2 Recruitment

Hertzog (2008) stated that for a feasibility study the sample numbers could be as low as 10 to 15 participants. However, it was decided that increasing this number to 20 participants: 20 individuals with dementia, their informal carer (20) and formal carer (20) for this study would provide for incomplete data sets or participant withdrawal. The total number of potential participants was 81(collected July 2013 - July 2014), with 28 sets of questionnaires distributed. There were 15 completed multi-informant sets (36 actual participants; 15 individuals with dementia, 15 informal carers and six Registered Nurses) returned for analysis.

Reasons for informal carer non-participation were not formally requested and pursuing the grounds for non-participation was not agreed at ethical review. However, explanations were volunteered and documented, including; length of questionnaire (n=1), lack of interest in the study (n=2), too complicated (n=1), and concerns over confidentiality and concerns over the welfare of the individuals with dementia (n=2). For an additional six non-participants, no reasons for non-participation were volunteered.

<u>Barriers to mental health research</u> – These include confidentiality concerns, distrust of the researcher, or a perception that harm would be inflicted (Woodhall, Morgan, Sloan, and Howard, 2010). These barriers were considered and discussed at the ethical review process. It was perceived that the only inconvenience for the informal carers would be time commitment (approximately 20-30 minutes) for completing the Adapted-SIDQ. However, the informal carer's willingness to participate in this study was much overestimated.

Law, Starr and Connelly (2011) claimed that only 3% (n=514) of participants felt studies needed to be conducted within specialist dementia care wards, with other research priorities (early detection of dementia, drug trials and carer support studies) taking prominence. This may account for the low engagement rates for the informal carers, as they did not perceive that a research study within an acute psychiatric assessment ward was a high priority.

Admission to hospital for a person with dementia and the impact on their relatives or carers is a challenging experience. Constant reminders related to participating in the study, with the potential stress this could induce would not be in-keeping with research ethics or research governance. On reflection, full consideration was not given to the potential impact the study could have on the informal carers, or the consequence of their non-participation. Further avenues of support would need to be provided for informal carers, perhaps including the self-identity domains in discussions when collecting background and collateral history from relative and family members upon admission to hospital.

Length of recruitment phase – It was planned to complete the data collection for the study in six months. However due to reduced numbers (lack of informal carer involvement and reduced numbers of patient admissions expected to Ward A and C resulted in delays and had a negative impact on the length of the recruitment for the study). Thus, the study recruitment lasted 12 months (July 2013 – July 2014) as opposed to the forecast six months period envisaged. It took, therefore, one a year to collect the 15 completed multi-informant sets (36 actual participants; 15 individuals with dementia, 15 informal carers and six Registered Nurses) available for final analysis. Whilst this did not meet the target number originally set at 20 for each informant group, the final number included in the study did fall within the

meet the upper recommendation (10-15) for feasibility studies suggested by Hertzog (2008).

5.12.3 Response rates

Questionnaires were hand delivered, but on reflection, consideration should have been given to alternative methods of distribution. E-mail delivery was disregarded (and therefore not submitted to NRES for ethical approval), as using both e-mail and hand delivery of the questionnaire may have complicated the processes further, yet response rates may have improved. The convenience for participants would have been advantageous, as well as the speed of delivery. However, access to the internet, use of e-mail and IT literacy as well as variance in computers, software and internet connections, may have adversely complicated the data collection process.

5.12.4 Completeness of data

Due to the recruitment challenges of the informal carer group, the Standard Operating Procedure (SOP, Figure 4) was not practical. There were incomplete data sets, with only two of the three questionnaires (individual with dementia and formal carer) being completed. From 28 potential participants, there were 13 incomplete data sets, reasons for which included; informal carer did not complete and/or returned (n=9) informal carer not interested (n=1), carer stress (n=2) and too complicated (n=1).

Procedures were amended to ensure data collected reflected the required multi-informant design; informal carers were recruited first, and following consent and completion of the questionnaire, the individuals with dementia and formal carer

were included to guarantee a full data set. This was due to the latter two participant groups being consistent in the completion of the Adapted-SIDQ. This change ensured sufficient participant numbers for the feasibility study. Individuals with dementia who answered the questionnaire without informal carer participation provided information which was used for care planning and therapeutic interventions ensuring that the information collected was utilised despite not holding a formal role in the results of this study.

5.12.5 Additional limitations and potential solutions

Acceptability data - On reflection, there was no formal method implemented to gather acceptability data related not only to the questionnaire but also study processes. Throughout the study, anecdotal information was noted when volunteered, but there was no requirement by those who chose not to be involved in the study to provide details for non-participation. This failure to collect acceptability data contributed to challenges in fully evaluating whether the Adapted-SIDQ was acceptable to the multi-informant participants. In future, this could be addressed through a comments box at the end of the questionnaire inviting their feedback on completing the questionnaire. Alternatively the questionnaire could have a tick box asking whether they would like to be contacted by the researcher post questionnaire completion, through a follow up post card for feedback or a phone call to gather this fundamental data.

Dual role of informal carer - The distinction between the informal carer as participant, and the informal carer in a Personal Consultee role was vague with an unclear recruitment pathway. However, at no time did any informal carer request

further clarification of this role other than what was provided by myself, or ward nursing staff, who understood and were conversant with all aspects of the study.

Study site – The application to National Research Ethics Service requested the study to be implemented in only one site, with potential recruitment across the three Older Persons Mental Health (OPMH) wards. The restriction of having ethical agreement for only one site had an impact on recruitment. A multi-centre study with access to similar care environments in the region, with the same or a longer period of data collection, could have potentially boosted recruitment numbers.

Registered Nurse response bias -

Response bias is a term that refers to conditions or factors that take place during the process of completing questionnaires, potentially affecting the way responses are provided and a deviation in the results. The design of the research study involved the Registered Nurses completing the Adapted-SIDQ for each patient they were allocated as Named Nurse (the key worker responsible for the co-ordination of all nursing care) as they were expected to repeat the measure there was a risk of learned bias and respondent fatigue.

Completing a questionnaire is a learning experience for any participant about the nature of the research and expected answers in a study (Choi and Pak, 2005). The Registered Nurses may have thought about prior questionnaires (such as the first questionnaire they completed for the individual with dementia they were nursing) which would then affect their answers to subsequent questionnaires. However as the questionnaire was to be completed by the Registered Nurse specific to an individual person, although the questions would be the same, the

answer provided would be different due to the self-identity of the patient with dementia for whom they were the Named Nurse for. Any Registered Nurse conducting an assessment with a patient has a professional duty to ensure that the individual is treated in a person centred manner when working with them.

A potential risk would be respondent fatigue, a documented phenomenon that occurs when participants become tired of the questionnaire and the quality of the data they provide begins to deteriorate (Lavrakas, 2008). It could potentially occur when the participants' attention and motivation drop when completing a questionnaire. The fatigue may have caused the Registered Nurses to answer "don't know", provide automatic answers, or not answer the questions at all. Fortunately none of these outcomes were noted when analysing the data, all questions were answered indicating that the Registered Nurses were able to maintain high levels of motivation and no fatigue was observed, reported not inferred from the completed questionnaires.

5.13 Implications for further research into self-identity and dementia using the Adapted Self-Identity in Dementia Questionnaire

Self-identity is a difficult concept to define, but using the definition proposed by Lemme (1999) which describes self-identity as the knowledge, feelings, and attitudes we have about our own being as unique, functioning individuals, this research study used the culturally Adapted-SIDQ to measure self-identity. There is a shortage of evidence measuring self-identity of persons living with dementia. Currently there is no one superior tool for measuring self-identity. This study set out to culturally adapt the validated SIDQ for use in a new country, clinical setting,

and with a new population of individuals living with dementia, their informal and formal carers.

This feasibility study has identified that the Adapted-SIDQ does have its uses within acute psychiatric care, such as gathering information about the individuals with dementia which would otherwise not have been collected. What is important then is how the information of self-identity is utilised for practical care planning for people with dementia. Following the original work of Cohen-Mansfield et al. (2000) and the SIDQ, their research focussed on the role of identity based preferences and positive engagement with people with dementia. There is a need to review how this information could practically be used within the assessment process of individuals with dementia when they are admitted for assessment and treatment of their mental health needs to a psychiatric in-patient ward.

Exploring the areas identified in Figure 42 as a focus for future research will contribute to attaining this goal.

FURTHER ADAPTATION OF QUESTIONNAIRE

• Adapting the SIDQ further to a shorter, more succinct questionnaire to collect the same level of data, but with the capacity for free text and extension on all aspects of self-identity and include pictoral aspects. To review how the data obtained from the questionnaire can be used in a format that is useful for all involved in the care of the individual.

ADAPTATION OF METHOD OF IMPLEMENTATION

• For the questionnaire to be administered for informal carers to improve engagement and partnership working, with an interview design to enable a less structured format to allow exploration of aspects of self-identity for the individuals with dementia.

SAMPLING AND POPULATION CONSIDERATIONS

• Determination of when the most effective stage of the illness would be to collect the required self-identity data.
• Further evaluation of the need for a multi-informant approach.

INTEGRATION OF SIDQ INTO ASSESSMENT PROCESS

• Potential use of the SIDQ at diagnosis through advanced care planning, integrating elements of the Adapted-SIDQ into the pre-existing physical and mental health assessment paperwork and amalgamating the questionnaire into a recovery model approach to dementia care.

TRAINING AND DEVELOPMENT SCOPING EXERCISE

• Through education and training, all the multi-disciplinary team to collect aspects of self-identity data to develop an understanding of the individuals with dementia to inform care planning and improve patient outcomes by ensuring continuity of care.

TRIAL TO ASSESS PATIENT OUTCOMES

• A comparison of patient outcomes between use and non-use of the Adapted-SIDQ, or how the Adapted-SIDQ can support individuals with dementia at crisis point in their illness progression.

Figure 42 Areas for further investigation related to the Adapted Self-Identity in Dementia Questionnaire

Key questions for future research have been stimulated related to the self-identity of the person with dementia from this study;

- Would a multi-centred approach over a similar or longer recruitment period be effective increasing study numbers?

- Would advanced care planning including self-identity information have a significant impact on the well-being and outcomes for the person with dementia?

- What impact does the acute psychiatric in-patient environment have on the self-identity of individuals with dementia?

- What would the impact of education and training of healthcare staff working within the acute psychiatric environment have on self-identity preservation for individuals with dementia?

- An evaluation of the impact of an increased awareness of self-identity by informal and formal carers on the well-being and outcomes of individuals with dementia.

The multiple informant approach was useful in this study, but the methods by which this information is collected may require further exploration to ensure consistency of approach and consistency of response. As the Adapted-SIDQ information is collected in the same way within this questionnaire, if similar information was collected in a different way runs the risk of collecting different information. The Adapted-SIDQ allows for comparisons to be made between multi-informants, but in the future it may not be required to obtain the informal and formal carers views, and instead focus on the lived experiences of those living with dementia.

In order to integrate the Adapted-SIDQ into the assessment processes when older adults are admitted to psychiatric in-patient wards there would need to be further research (potentially involving additional study sites).

Finally, it would be beneficial to evaluate if collecting self-identity information through the Adapted-SIDQ had an impact on patient outcomes. Through utilising a complementary measure such as Dementia Care Mapping (Kitwood and Bredin, 1992b) an evaluation of the acute psychiatric in-patient ward could provide insight to the quality of interaction and how this impacts on the individual living with dementia within the study setting. Therefore measuring before and after admission, making comparisons between the two time periods, noting the effect interaction and environmental influences potentially have on the individual's self-identity, and assessing whether there are correlations to changes in self throughout the admission process.

These questions highlight further areas of exploration with regard to self-identity in dementia potentially using the Adapted-SIDQ. This study has built upon the work of Cohen-Mansfield et al. (2000), ascertaining it was feasible to measure self-identity with an Adapted-SIDQ in an acute in-patient assessment ward. Appreciation of aspects of self in those with dementia can provide support and continuity and contribute to well-being.

5.14 Clinical implications of the study for dementia nursing practice

The results from this study provided an indication that the Adapted-SIDQ could be of clinical benefit in relation to self-identity in people with dementia. Throughout the study, both informal and formal carers felt that self-identity could be enhanced and that those individuals with dementia would positively benefit from this in some way. The findings have emphasised the importance of integrating and implementing four fundamental areas of nursing practice; care planning, continuity of care for those with dementia, therapeutic relationships with the patient and relatives, and training and development for clinical staff working with individuals with dementia.

Care planning - Personalised care planning is a collaborative process which aims to ensure that individual values and wishes influence the way their health needs are managed (Reuben and Tinetti, 2012). Person centred care involves tailoring an individual's care to their history, hobbies and interests, and abilities, reflecting what is important to them. From this study and that of Cohen-Mansfield et al. (2000), there was variation in preferences of what was important to the individual, which emphasises the need for exploring each person's specific needs. This cannot be achieved unless there is a formalised, systematic way to gather the data through a tool such as the Adapted-SIDQ. It effectively gathered information pertinent to the patients past and present life, indicating how important these aspects of self-identity were to the patient.

Continuity of care for individuals with dementia - Interventions aimed at promoting continuity of care from the beginning to the end of the patient's journey have been demonstrated to improve patient outcomes and provide safe and high-quality care (Sonola, 2012). Practical solutions to ensuring continuity arise from utilising a named nurse system, effective care planning (Cornwell, Levenson, Sonolaand

Poteliakhof,2012), and sharing and communicating pertinent information and knowledge that has been garnered from multiple informants about the patient. Cohen-Mansfield et al. (2000) identified the benefits of using the self-identity questionnaire as a starting point for this continuity, with life history discussions between the individual, family members and staff being implemented. Enhancing their care environment to provide connections to their past and present lives through using what is important to them and their preference of name, or personal objects, mementos or photographs is essential. The patient related self-identity data gathered throughout this study was used in handover to appropriate care homes if a supported placement was required upon discharge from the acute psychiatric in-patient ward, thus contributing to the continuity of care.

Therapeutic relationships - A focus on relationships and communication can improve continuity of self along the patient journey. The "Triangle of Care" (RCN, 2013b, Figure 1) emphasises the need for effective communication between health and social care professionals, individuals with dementia and their carers, and working in a partnership to meet personal, emotional, physical and psychological needs of those with dementia. This can only be accomplished if the strong correlation between nurse and patient is recognised and acted upon (Nicholson et al., 2010) whilst involving them in care delivery in a respectful manner, protecting the individual's sense of dignity and independence through using a tool such as the Adapted-SIDQ.

Training and development of staff - Poor staff skills and knowledge were identified by Surr, Smith, Crossland and Robins (2016) as a key contributor to reported poor outcomes for people with dementia within an acute hospital setting. From this study, it was demonstrated that, through educational sessions for formal carers,

self-identity was a topic worth researching in greater detail, and it upskilled the HCSW on the ward as they were made aware of the importance of recognising a patient's sense of self and utilising this information to inform care planning and treatment. Implementation of the Adapted-SIDQ in the clinical area would have training and development implications for nursing and allied health staff. Recognition of the role of nursing staff and allied health professionals as part of the "Triangle of Care" to initiate discussions focusing on self-identity is an identified need. Employed members of nursing staff such as HCSW are given a thorough induction and learn through practical and clinical experience on assessing, treating and supporting people with dementia. There is no formal training for this within Ward A. Registered Nurses have had training throughout their nursing course and possible post graduate training on dementia care. Agency staff receive no formal training on dementia care. Student nurses have education and training in the implementation of person centred care prior to their placements, but there is an assumption that this staff group possess the knowledge and skills required to implement a person centred care approach, which is often not the case. A comprehensive and effective training programme on selfhood, the principles of person centred care (Kitwood, 1997), and the use of tools such as the Adapted-SIDQ are indicated to ensure preservation of self-identity in individuals with dementia when admitted to an acute psychiatric in-patient environment and actively change the perception that dementia is still described as a "living death" (Hill, 2008).

In summary, the study has identified that there is a clinical need to use a validated tool to gather self-identity data and use this as a basis for intervention for those with dementia. The Adapted-SIDQ could provide a method of accomplishing this,

but is likely to require further refinement and testing before its expansion and adoption as a clinical tool.

5.15 Conclusions

These findings suggest that it is feasible to measure self-identity in dementia using the Adapted-SIDQ. The original SIDQ was adapted using co-design with stakeholders, and following the adaptation process, the tool was able to ascertain information on the individual's preferences of four self-identity dimensions in past and present time frames. The self-identity in individuals with dementia was able to be ascertained when they were admitted to an acute psychiatric hospital for older adults.

In this study the Adapted-SIDQ was able to elicit positive self-identity responses from individuals with mild to severe cognitive impairment. Through providing person centred, individualised support, the questionnaire was answered, providing fundamental information to inform care interventions for those with dementia.

The Adapted-SIDQ was able to identify the self-identity roles that individuals living with dementia identified with and the strength of these roles in the past and present. The extent of agreement between the individuals with dementia, informal carer and formal carers about the importance of self-identity was established.

Finally, the Adapted-SIDQ was an acceptable, practical and appropriate tool for use within a research study, but identified limitations throughout the study would need to be addressed prior to any further research using the Adapted-SIDQ.

The next chapter reflects on the personal and professional challenges associated with the Professional Doctorate in Nursing and the learning and development associated with the completion of this study.

Chapter Six – REFLECTIONS ON THE PROFESSIONAL DOCTORAL JOURNEY

As part of the learning journey involved in the Professional Doctorate in Nursing, reflection on the experience is pivotal to gaining insight to personal learning and development. This introspection will review aspects of the course from the past nine years, considering my academic and professional learning, motives, motivations and emotions to use as a catalyst for further individualised development and progression.

6.1 Reflection

Reflection is a difficult notion to define, and Cooney (1999) states most definitions are often too vague, yet Haddock and Basset (1997, p.39) offer a definition which describes reflection as *"thinking purposefully about clinical practice to gain new insights ideas and understanding"*. This definition proposes that reflection is not merely describing an event but it is a conscious, deliberate process (Atkins and Murphy, 1995) which we can use to analyse and interpret the experience in order to change perceptions and practices. According to Jones (1999), reflection has been adopted and adapted by the nursing profession to demonstrate the analytical component required by all nurse practitioners, and Saylor (1990, cited in James and Clarke, 1994, p.83) goes on to stress that reflection addresses the balance between the scientific basis of nursing and the mastery and creativity of the profession.

Atkins and Murphy (1995) state that the capacity for an individual to reflect requires certain attitudes, qualities and skills, including a certain degree of self-awareness of own beliefs and value systems, being conscious of personality, the

ability to describe accurately thoughts and feelings, capturing the essence of the situation. They stress that there is a need to synthesise and integrate new knowledge with pre-existing knowledge to solve future problems from a different, learned perspective.

I intend to reflect on, explore and capture aspects of my doctoral journey in terms of what Johns (2000, p.34) describes as "*a window through which the practitioner can view and focus self within the context of her own lived experience*". I will reflect on the research process and the involvement of individuals with dementia in research, personal reflections on the academic challenges, how the course has affected my professional identity and finally, personal challenges encountered.

Embarking on the Professional Doctorate in Nursing enabled me to explore and extend my professional experience, linking my desire to conduct a study involving those with dementia and improving clinical dementia care and practices, with a strong clinical focus "*to develop new ideas and new knowledge through rigorous approaches*" (Fulton, Kuit, Sanders, and Smith, 2012, p.132), yet setting out progression within my chosen career pathway.

6.2 Impact of the research process

San Miguel and Nelson (2007, p.73) stress one of the core principles of professional doctorates ensures individuals "*undertake research that emerges from, and will be useful to their own workplace and profession*". I feel that this research study has benefited both the workplace and nursing profession associated with dementia care.

An initial element of my role as researcher was to implement aspects of the Mental Capacity Act (Department of Health, 2005),and this aspect of the research process allowed me to focus my assessment skills on a person with dementia's emotions, skills and abilities to enable them to have a voice when it came to aspects of their illness, as all too often people with dementia are excluded due to their cognitive impairments (Hellstrom et al., 2007).

The informal carer involvement was the greatest challenge within the research process and I needed to be aware of my own beliefs and prejudices, which may have hindered the research process. Individuals have the right not to participate and freedom to refuse, yet trying to understand reluctance from relatives to be involved in a study whereby we wanted to learn as much as possible from them to support and improve the well-being of those with dementia was difficult.

Reflecting on the inclusion of the formal carers in the study, I am proud of my nursing team who not only were able to contribute in the planning stages of the study but through engaging with the Registered Nurses, they in turn would have a positive attitude toward research utilisation within the clinical area (Lacey, 1994).

This study helped to develop and improve my transformational leadership skills (Ward, 2002), namely; authenticity in that my actions reflected my attitudes and beliefs related to my nursing practice, using my expertise and competence within dementia care nursing, sharing leadership where this was equal among all team members involved in the research study, and a common vision amongst the team to see positive nursing practices in action to create change for improved outcomes for the patients.

6.3 Impact of the Professional Doctorate in Nursing on the workplace

Since the late 1990's there have been frequent calls for nursing to become a research-based profession (Gill, 2004), with an emphasis on the development of a 'research culture' within all disciplines of nursing. This culture is derived from the need for evidence-based practice working towards clinical effectiveness and within the structure of clinical governance. This culture is characterised by receptiveness to the research process, education and training with a research focus, an environment of inclusivity, and finally support for doctoral and post-doctoral research. However, Andrew, Ferguson and McGuiness (2008) claim that practitioner-driven research such as that implemented through doctoral programmes often falls into the academic equivalent of a 'black hole' in nursing. Thompson (2003) argues that this negativity, lack of research productivity and effectiveness can be overcome through the organisation culture, values and philosophy. The research culture within my employing Trust, and where this study was implemented, has a positive and enabling vision regarding the importance of research with a clear research agenda (Wilkes and Jackson, 2013). This is evident in the Trust being shortlisted in the Clinical Research Impact category for the 2014 Health Service Journal (HSJ) labelled 'A Research Active Clinical Workforce'; it outlined the focus by which a research active and enthused clinical workforce had the chance to actively participate in research.

Through engagement with the ward-based team at the planning stages of the study, identifying stakeholders at the onset, their involvement in the Registered Nurse education sessions and forums, and of course actually completing the Adapted-SIDQ, they have all demonstrated a keen interest in the study. The

ward-based staff have also been interested in my progression throughout the doctorate course, asking me how I am getting on, and the inevitable question '*When will I finish*?' Their questioning communicates to me that they are interested in the research we conducted, reflecting the inclusivity required for a positive research culture.

6.4 Impact of the Professional Doctorate in Nursing on academic theory

The Professional Doctorate in Nursing has facilitated the contribution that I have made to academic theory on two levels -firstly the contribution made to published nursing press, and secondly through dissemination of my thesis.

Throughout the Professional Doctorate in Nursing course, I have been fortunate to have three published papers in nursing journals, two of which are associated with this thesis, listed in Table 22 (In full, Chapter 9).

Table 22 Successful publications from the Professional Doctorate in Nursing

Murray, A. (2011). The implementation of a self-administration of medication programmes within Older Persons Mental Health. *Journal of Psychiatric and Mental Health Nursing* **18 (2), 113-21.**

Murray, A. (2013). The mental capacity act and dementia research*. Nursing Older People* **25 (3), 14-20.**

Murray, A. (2014). The effect of dementia on patients, informal carers and nurses. *Nursing Older People* **26 (5), 27-31.**

The motivation to publish the second paper, detailing my journey through the ethical minefield of the Mental Capacity Act (Department of Health, 2005) in relation to research activities, evolved when working on my research study proposal. I faced a huge challenge in finding guidance and support from any other forum and I could share my learnt knowledge and experience of going through the Integrated Research Application System (IRAS) and provide a contemporary, 'real time' contribution to help others within the field of research with people with dementia. My experiences can now be accessed by other researchers trying to engage individuals who potentially lack capacity in research activities. Feedback from the Editor of the Nursing Older People journal through personal email has informed me that my article on the Mental Capacity Act and dementia research is on their 'most read' list in Nursing Older People, and has been cited by other researchers.

The impact of my written thesis on academic theory is yet to be determined. It is my aim that through dissemination of the research process and results, it will be demonstrated that an original piece of dementia care research has been undertaken.

6.5 Reflections on the academic challenges of the Professional Doctorate in Nursing

The Professional Doctorate course aims to refine academic skills such as developing reflective writing and critical appraisal skills, and writing at doctoral level with the potential for publication and dissemination of research throughout the duration of the course. I have been fortunate to have three papers published, which allowed me to achieve elements of Part One of the course in the Publication

and Dissemination Unit and two papers throughout Part Two of the doctorate course which helped me to focus my academic writing associated with my study and share my learning within my sphere of practice.

According to Honey and Mumford (1986), I have a strong inclination towards the reflector/theorist learning style, which identifies my optimum learning preference within a formal classroom environment. My learning experiences rely on logic, structure, rationality and goal-driven approaches to problem solving and progression (Rassool and Rawaf, 2007). I thrived within this structure, and despite facing academic challenges (presentations, adapting to writing at doctoral level and achieving the criteria demanded from the course curriculum), I felt a sense of achievement and was prepared for Part Two.

Part Two of the programme was a very different model; it moved from a highly-structured course to a far less prescriptive model, whereby the content was mostly student driven with progress derived from consultation and collaboration between student and supervisors, organised around the research element of the doctoral course. I found this adaptation a huge challenge, feeling anxious and isolated. I had responded well to the taught and supportive elements throughout Part One and this was no longer available. It was of paramount importance that I ensured that my supervisory team were well established to provide support and continuity.

There have been low periods when finding the motivation to continue was hard, but I believe maintaining a positive attitude towards the course helped, principally having a belief and passion in what I was doing, confronting the challenges head on, with a determination to succeed in gaining my doctoral qualification. One of my greatest achievements came at a particularly despondent moment when the

design and implementation of this study was presented to the National Research Ethics Service(NRES) whereby they questioned my ethics application. This learning process and the outcomes from it gave a huge boost to my confidence. This was the first time my study had been peer reviewed, with positive feedback being given. The continued camaraderie and support through friends from the course who experienced similar academic, professional and emotional challenges provided the impetus and drive to see the research study and course through to its completion.

Writing my thesis has been a huge learning experience, whereby the skills needed to critically write at doctoral level have been consolidated into a coherent, logical piece of work, which I hope has made a positive contribution to the knowledge we have related to dementia care. Throughout the journey of implementing the study I now know my limitations, what areas I need to develop further in, constraints faced, areas of strength and working within the processes and structures required to implement an ethically sound study.

6.6 Professional identity

Throughout this doctoral journey I believe I have focused on developing my professional identity, gaining a heightened awareness of what it is to be a nurse. I have looked at my professional nursing practice through a "lens" (Sanders, de Medeiros and Bartell, 2011) enabling me to question myself, my practice and my whole philosophy, utilising my existing knowledge and experience, transforming into an "expert" practitioner (Benner, 1982).

Schein (1987) defines professional identity as a "constellation" of attributes, beliefs, values, motives and experiences, the terms of which define them within a

professional role. Being able to provide care to those with dementia is central to the motivation for me to nurse, and is inextricably linked to the fact that I can continue to have a significant impact on improving my patients' well-being, in addition to a feeling of a sense of achievement and immense job satisfaction. I feel confident in my mental health nursing skills and how I support those people with dementia who experience the anxiety and distress associated with the illness, not the novice self-doubting nurse described in the Preface of this thesis.

These feelings of self-validation and achievement are in themselves motivational factors within the nursing profession (Coyle-Rogers and Cramer, 2005), inducing feelings of identity, especially when patients acknowledge the care they have received. However, nursing this cohort of patients, this acknowledgement is often absent, yet I have recognised that I positively contributed to the patients' wellness either through hands-on clinical nursing, influencing my nursing team through leadership or enhancing a culture conducive to person centred care.

6.7 Personal challenges

Wellington and Sikes (2006) studied the impact of professional doctorate programs on individuals' personal and professional lives. Reading through the excerpts from the students in their study, and how their lives had irrevocably changed throughout the experience, I can now empathise and understand their experiences. By reviewing my personal challenges from the course, insights to my character will aid understanding throughout this research journey.

Although compartmentalisation is a term used within psychiatry and psychology, the model of compartmentalisation of self-structure (Zeigler-Hill and Showers, 2007) can be adapted to explain how I have used coping mechanisms over the

past nine years to manage the different challenges and demands the roles of mother, partner, nurse manager and student pose. It has been advantageous to effectively manage time, develop and submit assignments, publish papers, conduct research based activities and attend tutorials. I have felt that I have been able to focus more on one aspect of one problem or challenge, rather than generalising too much, maintaining an equilibrium of all competing roles by creating boundaries that have been drawn physically and established mentally.

On a personal level, I have used compartmentalisation as a coping mechanism of the demands made on my time by the course, as well as my professional and private life. I believe that I have met the challenges demanded of me and drawn strength from this doctoral course; working clinically developing expertise within my profession, generating and developing academic knowledge and skills, completing an independent research study linked to professional practice, and growing as an advanced practitioner within dementia care.

These learning experiences, challenges and areas of development have culminated in a successful application and commencement of the Trainee Nurse Consultant Programme for Mental Health through Health Education England (Wessex) in April 2015.

6.8 Chapter Summary

The introspection and exploration of my immeasurable learning over the past nine years throughout this doctoral programme cannot be easily summarised in these brief paragraphs; my development has been complex and challenging, both in positive and negative ways, but every experience has provided positive outcomes with learning and development about me as a person.

Chapter Seven - REFERENCES

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Chapter Eight - APPENDICES

Appendix 1: Original Self-Identity in Dementia Questionnaires.

Appendix 2: Research Ethical Committee approved paperwork for Adapted Self-Identity Questionnaires.

Appendix3: University of Portsmouth Form UPR16 Research Ethics Review Checklist

Appendix 4: Adapted Self-Identity in Dementia Questionnaires.

Appendix 1: Original Self-Identity in Dementia Questionnaires;

    (i)   Self-Identity in Dementia Questionnaire – Nursing home resident

    (ii)   Self-Identity in Dementia Questionnaire – Nursing home family

    (iii)   Self-Identity in Dementia Questionnaire – Nursing home staff

Self Identity Questionnaire – Nursing home resident

Date

Name of participant

COULD NOT COMPLETE?

  1=Yes

  2=No

What was your main job/occupation? If there were several choose the most important.

  2=Engineer

  1=Homemaker

  3=Military personnel

  4=Lawyer

  5=Doctor

  6=Professor

  7=Clerk/Secretary

  8=Construction worker

  9=Sales person/Business

  10=Artist (writer, painter, musician, etc)

  11=Farmer

  12=Accountant

  13=Teacher

  14=Architect

  15=Security/law enforcement

  16=Nurse

  17=Scientist

18=Factory worker/Manufacturing

19=Owner of business/Administrator

20=Had none

21=Do not know

22=Other

Other: Specify_____

How important s this job/occupation to you today?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

How important was this job/occupation to you in the past?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

Have you ever been married?

1=Yes

2=No

3=Do not remember

Is your husband/wife alive?

1=Yes

2=No

3=Not relevant

4=Do not remember

Are you divorced?

1=Yes

2=No

3=Not relevant

4=Do not remember

Do you have children?

1=Yes

2=No

3=Do not remember

Are your children alive?

1=Yes

2=No

3=Not relevant

4=Do not remember

Which family relationship/role was most important for you?

1=Being a spouse

2=Being a parent to children

3=Being a son/daughter to your parents

4=Being a friend

5=Being a sister/brother

6=Being a son/daughter in law

7=Being a grandparent to his/her grandchildren

8=Do not remember

9=Did not have any family relationships

10=Other

Other: Specify_____

How important was this relationship to you in the past?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

How important is this relationship to you in the today?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

What are some of your favorite things to do (other than work)?

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Reading/Studying

  1=Yes

  2=No

Gardening

  1=Yes

  2=No

Painting

  1=Yes

  2=No

Helping others

  1=Yes

  2=No

Traveling

  1=Yes

  2=No

Watching TV, Movies/Videotapes

  1=Yes

  2=No

Cooking   1=Yes

  2=No

Discussing politics/current events

  1=Yes

  2=No

Chapter Eight: Appendices

Writing

  1=Yes

  2=No

Socializing/spending time with friends

  1=Yes

  2=No

Cards/word games/Crossword puzzles

  1=Yes

  2=No

Collecting (stamps, books, etc.)

  1=Yes

  2=No

Crafts (sewing, knitting etc)

  1=Yes

  2=No

Caring for pets

  1=Yes

  2=No

Listening to or playing music

  1=Yes

  2=No

Woodworking

  1=Yes

2=No

Telling jokes/stories

  1=Yes

  2=No

Physical activities (dancing, walking, sports etc,)

  1=Yes

  2=No

Religious activities

  1=Yes

  2=No

Eating/ Tasting food

  1=Yes

  2=No

Trips outside Nursing home

  1=Yes

  2=No

Not relevant, Never had leisure time

  1=Yes

  2=No

Do not remember

  1=Yes

  2=No

Comments:_____

How important were these hobbies/activities to you in the past?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

How important are these hobbies/activities to you today?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

Specific information_____

In which things are you especially proud (could be personal achievements, special traits, a special past, etc)

Beauty/Fitness

1=Yes

2=No

Artistic achievements

1=Yes

Chapter Eight: Appendices

   2=No

Family heritage

   1=Yes

   2=No

Financial assets, Economic achievements

   1=Yes

   2=No

Success of a family member

   1=Yes

   2=No

Devotion to work

   1=Yes

   2=No

Devotion to family

   1=Yes

   2=No

Knowledge/Intelligence/Wisdom

   1=Yes

   2=No

Service/Contribution to country

   1=Yes

   2=No

Traits

1=Yes

2=No

Birthplace

1=Yes

2=No

Friends/Social achievements/popularity

1=Yes

2=No

Surviving ability

1=Yes

2=No

Academic achievements

1=Yes

2=No

Selflessness/self-sacrifice

1=Yes

2=No

Honesty/fairness/trustworthiness

1=Yes

2=No

Do not have any personal achievements or attributes

1=Yes

2=No

Past experience (e.g. Holocaust)

  1=Yes

  2=No

Specify:_____

Do not remember

  1=Yes

  2=No

Other: Specify_____

How important were these achievements/attributes to you in the past?

  1=Not at all important

  2=Slightly important

  3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

How important are these achievements/attributes to you today?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not remember

Specific Information

What do you like doing here?

Reading/Studying

1=Yes

2=No

Gardening

1=Yes

2=No

Painting

1=Yes

2=No

Chapter Eight: Appendices

Volunteering

  1=Yes

  2=No

Talking about the past

  1=Yes

  2=No

Watching TV

  1=Yes

  2=No

Cooking   1=Yes

  2=No

Discussing politics

  1=Yes

  2=No

Writing

Socializing/spending time with friends

  1=Yes

  2=No

Listening to stories

  1=Yes

  2=No

Cards/word games/Crossword puzzles

  1=Yes

2=No

Telling jokes/stories

1=Yes

2=No

Physical activities (dancing, walking, sports etc)

1=Yes

2=No

Refreshments/meals

1=Yes

2=No

Watching others

1=Yes

2=No

Likes to do nothing

1=Yes

2=No

Collecting (stamps, books etc.)

1=Yes

2=No

Crafts (sewing, knitting etc.)

1=Yes

2=No

Caring for pets

1=Yes

2=No

Specific Information:_____

What do you like doing here?

Listening to or playing music

1=Yes

2=No

Woodworking

1=Yes

2=No

Watching movies

1=Yes

2=No

Trips outside the home

1=Yes

2=No

Religious activities

1=Yes

2=No

Discussion groups

1=Yes

2=No

Speaking about family and friends

　1=Yes

　2=No

Do not like anything

　1=Yes

　2=No

Looking at pictures of family or friends/using photos from the past

　1=Yes

　2=No

Do not know

　1=Yes

　2=No

Other: Specify_____

What do you like to do but cannot do here?

Reading

　1=Yes

　2=No

Gardening

　1=Yes

　2=No

Painting

　1=Yes

　2=No

Chapter Eight: Appendices

Volunteering

Talking about the past

  1=Yes

  2=No

Watching TV

  1=Yes

  2=No

Cooking   1=Yes

  2=No

Discussing politics

  1=Yes

  2=No

Writing

  1=Yes

  2=No

Socializing/spending time with friends

  1=Yes

  2=No

Listening to stories

  1=Yes

  2=No

Cards/word games/Crossword puzzles

  1=Yes

2=No

Telling Jokes/stories

1=Yes

2=No

Physical activities (dancing, walking, sports etc)

1=Yes

2=No

Refreshments/Meals

1=Yes

2=No

Watching others

1=Yes

2=No

Likes to do nothing

1=Yes

2=No

Collecting (stamps, books, etc)

1=Yes

2=No

Crafts (Sewing, knitting etc)

1=Yes

2=No

Caring for pets

1=Yes

2=No

Specific Information

What do you like to do but cannot do here?

Listening or playing music

1=Yes

2=No

Woodworking

1=Yes

2=No

Watching movies

1=Yes

2=No

Trips outside nursing home

1=Yes

2=No

Religious activities

1=Yes

2=No

Discussion groups

1=Yes

2=No

Speaking about family and friends

  1=Yes

  2=No

Do not like anything

  1=Yes

  2=No

Looking at pictures of friends or family/using photos from the past

  1=Yes

  2=No

Do not know

Other: Specify_____

What language do you like to speak?

  1=English

  2=Other

Specify: language_____

How would you like the staff to refer to you?

  1=By your first name   2=By your nickname   3=Dr.

  4=Professor   5=Mr. or Mrs.

  6=Do not know

  7=Other

Specify_____

Jiska Cohen-Mansfield, 2003

Self Identity Questionnaire – Nursing home Family

Date:_____

Name of Participant_____

Relationship of the family member to the participant

  1=Son

  2=Daughter

  3=Husband

  4=Wife

  5=Brother

  6=Sister

  7=Friend

  8=Grandson

  9=Granddaughter

  10=Son-in-law

  11=Daughter-in-law

  12=Other

Specify Relationship_____

Marital Status of participant

  1=Single

  2=Married

  3=Widowed

  4=Seperated

  5=Divorced

  6=Other

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Specify Marital Status _____

Number of children alive   _____

Number of children dead _____

Religion _____

Place of birth

  1=United States of America

  2=Foreign

Specify Place of birth _____

Year of Immigration _____

Comments _____

What level of education did your relative attain?

  1=Completed part of elementary school

  2=Completed elementary school

  3=Completed part of high school

  4=Completed part of undergraduate school

  5=Bachelor' s degree

  6=Graduate studies

  7=Other

Specify level of education _____

What was your relative's main occupation? If she /he had several, choose the one that was the most meaningful   1=Engineer

  2=Homemaker

3=Military personnel

4=Lawyer

5=Security/Law enforcement

6=Sales person/Business

7=Clerk/secretary

8=Professor

9=Farmer

10=Owner of business/administrator

11=Accountant

12=Teacher

13=Architect

14=Doctor

15=Scientist

16=Factory worker/manufacturing

17=Construction worker

18=Nurse

19=Artist (writer, painter, musician, etc)

20=Do not know

21=Had none

22=Other

Specify Main Occupation_____

For how many years did your relative work at this job?

1=_____ Years

2=Most of his/her adult life

3=Do not know

4=Not relevant

Specify Number of years_____

In the years that your relative worked in this job, how many hours a day did he/she dedicate to it?
1=Full time

   2=Part time

   3=Not relevant

   4=Do not know

How important was this profession/occupation to your relative in the past?

   1=Not at all important

   2=Slightly important

   3=Moderately important

   4=Important

   5=Very Important

   6=Do not know

   7=Not relevant

How important is this profession/occupation to him/her today?

   1=Not at all important

   2=Slightly important

   3=Moderately Important

   4=Important

   5=Very important

   6=Do not know

   7=Not relevant

Comments_____

How often does he/she talk about this occupation?

   1=Not at all

2=Rarely

3=Several times a week

4=Everyday or nearly everyday

5=Most of the time

6=Do not know

7=Not relevant

How often does his/her behavior show that this was his/her occupation?

1=Not at all

2=Rarely

3=Several times a week

4=Everyday or nearly everyday

5=Most of the time

6=Do not know

7=Not Relevant

Specify_____

In the years that your relative worked in this job, what was his/her attitude toward this occupation/job?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Do not know

6=Not relevant

What is his/her attitude toward this occupation/job today?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Do not know

6=Not relevant

Comments_____

Which family relationship, do you feel, is most important for the participant?

1=Being a sister/brother

2=Being a grandparent to his/her grandchildren

3=Being a son/ daughter in law

4=Being a friend

5=Being a spouse

6=Being a parent

7=Being a son/daughter to his/her parents

8=Has none

9=Do not know

10=Other

Other: Specify_____

How important were these relationships to him/her in the past?

1=Not at all important

2=Slightly important

3=Moderately Important

4=Important

5=Very important

6=Do not know

7=Not relevant

How important is this relationship to him/her today?

1=Not at all important

2=Slightly important

3=Moderately Important

4=Important

5=Very important

6=Do not know

7=Not relevant

How often does he/she talk about this relationship?

1=Not at all

2=Rarely

3=Several times a week

4=Everyday or nearly everyday

5=Most of the time

6=Do not know

7=Not relevant

How often does his/her behavior show that this was his/her most important relationship?
1=Not at all

2=Rarely

3=several times a week

4=Everyday or nearly everyday

5=Most of the time

6=Do not know

7=Not relevant

Comments_____

What do you feel is his/her attitude toward this relationship in the past?

   1=Positive

   2=Both positive and negative

   3=Negative

   4=Indifferent

   5=Do not know

   6=Not relevant

What do you feel is his/her attitude toward this relationship today?

   1=Positive

   2=Both positive and negative

   3=Negative

   4=Indifferent

   5=Do not know

   6=Not relevant

What are his/her favorite hobbies/leisure activities?

Reading

   1=Yes

   2=No

Gardening

   1=Yes

   2=No

Painting

   1=Yes

   2=No

Chapter Eight: Appendices

Traveling

  1=Yes

  2=No

Helping others

  1=Yes

  2=No

Watching movies/Videotapes

  1=Yes

  2=No

Writing

  1=Yes

  2=No

Socializing/spending time with friends

  1=Yes

  2=No

Eating, tasting food

  1=Yes

  2=No

Cards/games/crossword puzzles

  1=Yes

  2=No

Crafts (sewing, knitting, etc)

  1=Yes

2=No

Cooking   1=Yes

2=No

Discussing politics

1=Yes

2=No

Watching TV

1=Yes

2=No

Caring for pets

1=Yes

2=No

Collecting (stamps, books, antiques etc)

1=Yes

2=No

Listening or playing music

1=Yes

2=No

Woodworking

1=Yes

2=No

Telling jokes/stories

1=Yes

2=No

Physical activities (dancing, walking, sports etc)

1=Yes

2=No

Walks or trips outside the facility

1=Yes

2=No

No hobby

1=Yes

2=No

Do not know

1=Yes

2=No

Other: specify_____

Comments_____

How important were these hobbies/activities to him/her in the past?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Do not know

7=Not relevant

How important are these hobbies/activities to him/her today?

   1=Not at all important

   2=Slightly important

   3=Moderately important

   4=Important

   5=Very important

   6=Do not know

   7=Not relevant

How often does he/she talk about these hobbies/activities?

   1=Not at all

   2=Rarely

   3=Several times a week

   4=Everyday or nearly everyday

   5=Most of the time

   6=Do not know

   7=Not relevant

How often does his/her behavior show that this was his/her hobbies/leisure activities?
1=Not at all

   2=Rarely

   3=Several times a week

   4=Everyday or nearly everyday

   5=Most of the time

   6=Do not know

   7=Not relevant

What was his/her attitude towards these hobbies/activities in the past?

   1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Do not know

6=Not relevant

What was your relative's attitude towards these hobbies/activities today?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Do not know

6=Not relevant

Specific Information_____

Of which personal achievement, special traits or attributes was your relative especially proud?

Financial assets, economic achievements

1=Yes

2=No

Determination

1=Yes

2=No

Beauty/Fitness

1=Yes

2=No

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Artistic achievements

  1=Yes

  2=No

Birth-place

  1=Yes

  2=No

Surviving ability

  1=Yes

  2=No

Contribution to country

  1=Yes

  2=No

Traits

  1=Yes

  2=No

Specify_____

Success of a family member

  1=Yes

  2=No

Academic achievements

  1=Yes

  2=No

Devotion to work

  1=Yes

  2=No

Devotion to family

  1=Yes

  2=No

Selflessness/self sacrifice

  1=Yes

  2=No

Knowledge/Intelligence/Wisdom

  1=Yes

  2=No

Honesty/fairness/trustworthiness

  1=Yes

  2=No

Friends/social achievements/popularity

  1=Yes

  2=No

Past experience (e.g. Holocaust)

  1=Yes

  2=No

Has none

  1=Yes

2=No

Do not know

1=Yes

2=No

Specify_____ How important were these achievements/traits to him/her in the past

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Do not know

7=Not relevant

How important are these achievements/traits to him/her today?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Do not know

7=Not relevant

How often does he/she talk about these achievements/traits?

1=Not at all

2=Rarely

3=Several times a week

4=Everyday or nearly everyday

5=Most of the time

6=Do not know

7=Not relevant

How often does his/her behavior show that this was his/her most important achievements/traits/attributes?

1=Not at all

2=Rarely

3=Several times a week

4=Everyday or nearly everyday

5=Most of the time

6=Do not know

7=Not relevant

Comments_____

What was his/her attitude towards these achievements or traits in the past?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Do not know

6=Not relevant

What was his/her attitude towards these achievements or traits today?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Do not know

6=Not relevant

Which family role/identity is most important for the participant now?

  1=As a professional/housewife

  2=As a family member, or other social role

  3=As someone with a hobby/leisure activity

  4=As someone with achievements/traits

  5=Other

  6=Has none

  7=Do not know

Other: Specify‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾

Comments Specify‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾

Does your relative have any identities or traits/occupations that are not based on/or were of minor importance in his/her past? if "yes" please specify   1=As a professional/housewife

  2=As a family member, or other social role

  3=As someone with a hobby/leisure activity

  4=As someone with achievements/traits

  5=Other

  6=Has none

  7=Do not know

Comments: specify‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾

When did this change in identity occur‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾

If there were changes in identity, what change is the most important?

  ‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾‾

If he/she had a change in identity what was your reaction to this change?

1=Very relieved

2=Relieved

3=Slightly relieved

4=Indifferent

5=Slightly painful

6=Painful

7=Very painful

What words, subjects or activities have a special effect on him/her (making him/her happier, more coherent, remember his/her identity etc)

Listening to music

1=Yes

2=No

Socializing/spending time with friends

1=Yes

2=No

Watching movies/videotapes

1=Yes

2=No

Trips outside the nursing home facility

1=Yes

2=No

Recalling memories, talking about certain events in the past

1=Yes

2=No

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Talking about family or friends

   1=Yes

   2=No

Cards/games/crossword puzzles

   1=Yes

   2=No

Looking at pictures of family or friends

   1=Yes

   2=No

What words, subjects or activities have a special effect on him/her (making him/her happier, more coherent, remember his/her identity etc)

Watching TV

   1=Yes

   2=No

Writing

   1=Yes

   2=No

Walking or other exercises

   1=Yes

   2=No

Spending time with pets

   1=Yes

   2=No

Religious activities/topics

   1=Yes

   2=No

Discussions groups (guest speakers/staff presentations)

   1=Yes

   2=No

Arts and crafts

   1=Yes

   2=No

Reading/studying

   1=Yes

   2=No

Discussing politics

   1=Yes

   2=No

Not relevant

   1=Yes

   2=No

Do not know

   1=Yes

   2=No

Other: Specify_____

What causes him/her to get especially angry, agitated or to behave differently than usual?

1=ADL activities (such as eating, using toilet, etc)

2=Watching television, news or movies

3=Dismissal time

4=Frustration during activity

5=Structured/ physical environment (such as locked doors, etc)

6=He/she does not get especially angry

7=starting new activity

8=Maintaining attention to activity

9=Frustration at disorientation to place

10=Other people's behavior

11=There is no consistency in events. I do not know

12=Other

Causes of agitation: Comments: Specify_____

Is it possible, in your opinion, to enhance the feeling of self-identity?

1=Yes

3=Somewhat/Maybe

2=No

4=Do not know

If enhancing the feeling of self-identity is possible, do you think this would contribute to your relative's sense of well-being?   1=Yes, it will contribute very much

2=Yes, it will contribute somewhat

3=It will not make a difference

4=No, it will cause some harm

5=No, it will cause a lot of harm

6=Do not know

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In which ways (such as certain activities, words or changing environment) could we, in your opinion enhance or cultivate the self-identity feelings of your relative?

Listening or playing music

   1=Yes

   2=No

Socializing/spending time with sounds

   1=Yes

   2=No

Watching movies/videotapes

   1=Yes

   2=No

Trips outside nursing home

   1=Yes

   2=No

Recalling memories, talking about certain events in the past

   1=Yes

   2=No

Cards/games/crossword puzzles

   1=Yes

   2=No

Talking about family or friends

   1=Yes

   2=No

Chapter Eight: Appendices

Looking at pictures of family and friends

  1=Yes

  2=No

Watching TV

  1=Yes

  2=No

Writing

  1=Yes

  2=No

Walking or other exercises

  1=Yes

  2=No

Eating, tasting food

  1=Yes

  2=No

Spending time with/caring for pets

  1=Yes

  2=No

Religious activities/topics

  1=Yes

  2=No

Discussion groups (guest speakers/staff presentations)

  1=Yes

  2=No

Arts and crafts

  1=Yes

  2=No

Reading/studying

  1=Yes

  2=No

Discussing politics/current events

  1=Yes

  2=No

Not relevant

  1=Yes

  2=No

Do not know

  1=Yes

  2=No

Other: please specify_____

Bringing furnishings (art, paintings, clothes, carpet, furniture etc) from home.

  1=Yes

  2=No

Specify:_____

What causes your relative to feel more who he/she is and what is important to him/her?

1=Family or friends visits

2=Going out of nursing home

4=Letters or cards from family friends

3=Other

Specify_____

Do you think that the way you see your relative is the same way the staff sees him/her in the subject of his/her self-identity?

1=The same

2=Somewhat different

3=Totally different

4=Do not know

Comments: Specify_____

What identity does it seem that your relative would like to preserve?

1=As someone with a job/profession/housewife

2=As a family person

3=As someone with a hobby/leisure time activities

4=As someone with achievements/unique traits

5=Do not know

6=Other

Comments: Specify_____

What language does your relative like to speak?

1=English

2=Other

Specify:_____

What kind of surroundings/environment does your relative prefer?

   1=Quiet

   2=Monotonous

   3=Stimulating

   4=Familiar environment

   5=New environment (places)

   6=Other

Specify:_____

Is this a change from the past?

   1=Yes

   2=No

By which name/title do you think the staff should refer to your relative?

   1=By his/her first name
2=By a nickname   3=Mr.
or Mrs.   4=Professor
5=Dr.

   6=Other

Comments; Specify_____

Comments_____

Jiska Cohen-Mansfield, 2003

Self Identity Questionnaire – Nursing home staff

Date of Interview_____

Participant's name_____

location   1=Adult
day care

  2=Nursing Home Unit

nursing home unit_____

Name of Staff Member

Role of staff Member

  1=LPN

  3=RN

  5=Nursing assistant

  2=Activities Coordinator
4=Private Caretaker   6=Other,
Specify:

Other: Specify_____

How long have you known the participant?_____

What was his/her profession/job? If there is more than one choose the most important.

  1=Engineer

  2=Homemaker

  3=Military personnel

  4=Lawyer

  5=Nurse

6=Sales Person/Business

7=Clerk/Secretary

8=Farmer

9=Owner of Business/Administrator

10=Artist

11=Accountant

12=Teacher

13=Architect

14=Security

15=Doctor

16=Scientist

17=Factory Worker/Manufacturing

18=Professor

19=Do not know

20=Has none

21=Other

Other: Specify_____

Was this his/her main profession/occupation in the past?

1=Yes

2=No

3=Do not know

In your opinion, how important is this occupation to him/her today?

1=Not at all important

2=Slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not know

How often does he/she talk about this job/occupation?

1=Not at all

2=Rarely

3=Several times a week

4=Everyday or nearly every day

5=Most of the time

6=Cannot talk

7=Not relevant

8=Do not know

How often does his/her behavior show that this was his/her occupation?

1=Not at all

2=Rarely

3=Several times a week

4=Every day or nearly every day

5=Most of the time

7=Do not know

6=Not relevant

Specify_____

In you opinion, what is his/her attitude toward this job/occupation?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Not relevant

6=Do not know

Which family relationship, do you feel, is most important for the participant?

1=Being a spouse

2=Being a parent to children

3=Being a son/daughter to his/her parents

4=Being a friend

5=Being a sister/brother

6=Being a son/daughter in law

7=Being a grandparent to grandchildren

8=Do not know

9=Does not have any family relationships

10=Other

Other, Specify_____

Was this his/her main relationship in the past?

1=Yes

2=No

3=Do not know

How often does he/she talk about this relationship?

1=Not at all

2=Rarely

3=Several times a week

4=Everyday or nearly every day

5=Most of the time

6=Cannot talk

7=Not relevant

8=Do not know

In your opinion, how important is this relationship to him/her today?

1=Not at all important

2=slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not know

How often does his/her behavior show that this was his/her most important relationship?
1=Not at all

2=Rarely

3=Several times a week

4=Every day or nearly every day

5=Most of the time

6=Do not know

7=Not relevant

Specify:_____

In your opinion, What is his/her attitude toward this relationship?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Not relevant

6=Do not know

What are his/her favorite hobbies/leisure time activities?

Reading   1=Yes

2=No

Gardening

1=Yes

2=No

Painting

1=Yes

2=No

Craft (sewing, knitting, etc.)

1=Yes

2=No

Helping others

1=Yes

2=No

Traveling

1=Yes

2=No

Cards/Games/Crossword puzzles

1=Yes

2=No

Caring for pets

1=Yes

2=No

Woodworking

1=Yes

2=No

Watching TV

1=Yes

2=No

Cooking   1=Yes

2=No

Discussing Politics

1=Yes

2=No

Writing

1=Yes

2=No

Listening or Playing music

1=Yes

2=No

Watching movies/Videotapes

1=Yes

2=No

Socializing/ spending time with friends

1=Yes

2=No

Collecting (stamps, books, etc)

1=Yes

2=No

Telling jokes/stories

1=Yes

2=No

Physical activities (dancing, walking, sports)

1=Yes

2=No

No hobby

1=Yes

2=No

Does not know

1=Yes

2=No

Other: Specify_____

Were these his/her main hobbies/leisure time activities in the past?

1=Yes

2=No

3=Do not know

In your opinion, how important are these hobbies/activities to him/her today?

1=Not at all important

2=slightly important

3=Moderately important

4=Important

5=Very important

6=Not relevant

7=Do not know

How often does he/she talk about these hobbies/activities?

1=Not at all

2=Rarely

3=Several times a week

4=Every day or nearly every day

5=Most of the time

6=Cannot talk

7=Not relevant

8=Do not know

How often does his/her behavior show that these were his/her hobbies/leisure activities?
1=Not at all

2=Rarely

3=Several times a week

4=Every day or nearly every day

5=Most of the time

6=Not relevant

7=Do not know

In your opinion, What is his/her attitude toward this hobby/activities?

1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Not relevant

6=Do not know

Specific Information

Which personal achievements, experiences or attributes are most important to the participant?

Beauty/fitness

1=Yes

2=No

Artistic achievements

1=Yes

2=No

Family heritage

1=Yes

2=No

Contribution to country

1=Yes

2=No

Success of a family member

1=Yes

2=No

Devotion to work

1=Yes

2=No

Devotion to family

1=Yes

2=No

Determination

1=Yes

2=No

Knowledge/intelligence/wisdom

1=Yes

2=No

Birth- place

1=Yes

2=No

Personal experience (e.g. Holocaust),

1=Yes

2=No

Personal experience: Specify_____

Friends/social achievements/popularity

1=Yes

2=No

Chapter Eight: Appendices

Surviving ability

  1=Yes

  2=No

Academic achievements

  1=Yes

  2=No

Selflessness/self-sacrifice

  1=Yes

  2=No

Traits

  1=Yes

  2=No

Honesty/Fairness/trustworthiness

  1=Yes

  2=No

Financial assets, economic achievements

  1=Yes

  2=No

Has none

  1=Yes

  2=No

Do not know

  1=Yes

  2=No

Other achievements/traits, Specify:_____

Were these his/her main achievements/traits/attributes in the past?

  1=Yes

  2=No

  3=Do not know

In your opinion, how important are these achievements/traits/attributes to him/her today?
1=Not at all important

  2=slightly important

  3=Moderately important

  4=Important

  5=Very important

  6=Not relevant

  7=Do not know

How often does he/she talk about these achievements/traits/attributes?

  1=Not at all

  2=Rarely

  3=Several times a week

  4=Every day or nearly every day

  5=Most of the time

  6=Cannot talk

  7=Not relevant

  8=Do not know

How often does his/her behavior show that these were his/her achievements/traits/attributes?
1=Not at all

2=Rarely

3=Several times a week

4=Every day or nearly every day

5=Most of the time

6=Not relevant

7=Do not know

In your opinion, What is his/her attitude toward these achievements/traits/attributes?
1=Positive

2=Both positive and negative

3=Negative

4=Indifferent

5=Not relevant

6=Do not know

Specific information_____

Which role or identity is most important for the participant now?

1=As a professional/housewife

2=As a family member or other social role

3=As someone with hobbies/leisure activities

4=As someone with achievements/traits

5=Has none

6=Do not know

7=Other

8=Comments

Other, Specify_____

Comments_____

Which new identity does the participant have that is not based on his/her past or was of minor importance?

   1=As a professional/housewife

   2=As a family member or other social role

   3=As someone with a hobby/leisure activity

   4=As someone with achievements/traits

   5=Has none

   6=Do not know

   7=Other

   8=comments

Other, Specify_____

Comments_____

Which identities does it seem to you that the resident would like to preserve?

   1=As someone with a job/profession/housewife

   2=As a family person

   3=As someone with a hobby/leisure time activity

   4=As someone with achievements/traits

   5=Do not know

   6=Other

Specify_____

Comments_____

Which roles do other residents of the nursing home see in participant?

   1=As a professional/housewife

   2=As a family member or other social role

   3=As someone with a hobby/leisure activity

   4=As someone with achievements/traits

   6=Do not know

   7=Others reject him/her

   8=Not relevant

   9=Other

   10=Comments

Other, Specify_____

Comments_____

Which words, subjects or activities have a special effect on the participant? (making him/her happier, more coherent, remembering his/her identity, etc)

Discussion groups (guest speakers/staff presentations)

   1=Yes

   2=No

Recalling memories, talking about certain events in the past

   1=Yes

   2=No

Discussing politics

   1=Yes

   2=No

Cards/Games/Crossword puzzles

   1=Yes

2=No

Talking about family/friends

1=Yes

2=No

Looking at pictures of family/friends, using photos from the past

1=Yes

2=No

Painting

1=Yes

2=No

Helping others

1=Yes

2=No

Cooking   1=Yes

2=No

Writing

1=Yes

2=No

Telling jokes/stories

1=Yes

2=No

Collecting (stamps, books, etc)

1=Yes

2=No

Watching TV, news, or movies

1=Yes

2=No

Woodworking

1=Yes

2=No

Religious activities/topics

1=Yes

2=No

Trips outside the nursing home

1=Yes

2=No

Socializing/spending time with friends

1=Yes

2=No

Listening or Playing music

1=Yes

2=No

Doing nothing

1=Yes

2=No

Observing/Watching others

  1=Yes

  2=No

Visiting with family member(s)

  1=Yes

  2=No

Specific Information:_____

Which words, subjects or activities have a special effect on the participant? (making him/her happier, more coherent, remembering his/her identity, etc)

Gardening

  1=Yes

  2=No

Going for a walk or other exercising

  1=Yes

  2=No

Eating/tasting food

  1=Yes

  2=No

Spending time with pets

  1=Yes

  2=No

Watching movies/Videotapes

  1=Yes

   2=No

Reading/ studying

   1=Yes

   2=No

Do not know

   1=Yes

   2=No

Not relevant

   1=Yes

   2=No

Other

   1=Yes

   2=No

Specify_____

What causes him/her to become agitated, behave differently than usual or angry?

_____

Watching TV, news, or movies

   1=Yes

   2=No

Dismissal time

   1=Yes

   2=No

Structured/physical environment (such as locked doors, etc.)

  1=Yes

  2=No

Starting new activity

  1=Yes

  2=No

ADL activities (such as eating, using toilet, etc.)

  1=Yes

  2=No

Frustration at disorientation to place

  1=Yes

  2=No

Other people's behavior

  1=Yes

  2=No

There is no consistency in events, I do not know

  1=Yes

  2=No

He/she does not get especially angry

  1=Yes

  2=No

Frustration during activity

  1=Yes

  2=No

Other_____

Specify_____

Is it possible, in your opinion, to enhance the feeling of self-identity

  1=Yes

  2=No

  3=Somewhat/maybe

  4=Do not know

If enhancing the feeling self-identity possible, do you think it will contribute to participant's sense of well-being?

  1=Yes, it will contribute a lot

  2=Yes, it will contribute somewhat

  3=It will not make a difference

  4=No , it will cause harm

  5=No, it will cause a lot of harm

  6=Do not know

In which ways could we, enhance or cultivate the self-identity feelings of the participant? (such as certain activities, words or changing the environment)

Discussion groups (guest speakers/staff presentations)

  1=Yes

  2=No

Recalling memories, talking about certain events in the past

  1=Yes

2=No

Discussing politics

1=Yes

2=No

Cards/Games/Crossword puzzles

1=Yes

2=No

Talking about family/friends

1=Yes

2=No

Looking at pictures of family/friends, using photos from the past

1=Yes

2=No

Painting

1=Yes

2=No

Helping others

1=Yes

2=No

Cooking   1=Yes

2=No

Writing

1=Yes

   2=No

Telling jokes/stories

   1=Yes

   2=No

Collecting (stamps, books, etc)

   1=Yes

   2=No

Watching TV, news, or movies

   1=Yes

   2=No

Religious activities/topics

   1=Yes

   2=No

Trips outside the nursing home

   1=Yes

   2=No

Socializing/ spending time with friends

   1=Yes

   2=No

Listening or Playing music

   1=Yes

   2=No

Chapter Eight: Appendices

In which ways could we, enhance or cultivate the self-identity feelings of the participant? (such as certain activities, words or changing the environment)

Gardening

  1=Yes

  2=No

Physical activities (dancing, walking, sports)

  1=Yes

  2=No

Doing Nothing

  1=Yes

  2=No

Furnishings (art, paintings, clothes, carpet, furniture) from home

  1=Yes

  2=No

Eating/tasting food

  1=Yes

  2=No

Woodworking

  1=Yes

  2=No

Spending time with pets

  1=Yes

  2=No

Watching movies/Videotapes

  1=Yes

  2=No

Reading/ studying

  1=Yes

  2=No

Craft (sewing, knitting, etc.)

  1=Yes

  2=No

Do not know

  1=Yes

  2=No

Not relevant

  1=Yes

  2=No

Other_____

Specify_____

Have there been changes in his/her feelings of self-identity over the course of his/her illness?

  1=Yes

  2=No

  3=Do not know

Specify Identity Changes_____

Do you think that the way you see the participant is the same as the way family sees him/her in the subject of his/her self-identity?

  1=The same

  2=Somewhat different

  3=Totally different

  4=Do not know

Specify_____

Do you have any other comments or suggestions concerning the self-identity of the participant?

Comments_____

Language Preference

  1=English

  2=Other

Specify language Preference_____

Does participant have environmental preferences?

  1=Quiet

  2=Monotonous

  3=Stimulating

  4=New environment

  5=Familiar environment

  6=Other

Specify environmental preferences_____-

By which name do you refer to the participant?

   1=By his/her first name
2=By a nickname   3=Mr. or
Mrs.

   4=Dr.

   5=Professor

   6=Other

Other_____

Jiska Cohen-Mansfield, 2003

Appendix 2: Research Ethical Committee approved paperwork for Adapted Self-Identity in Dementia Questionnaire;

- Project Procedural Checklist
- Your Life Story Information Sheet for Individuals with Dementia
- Mental Capacity Assessment for Consent to Participate in Proposed Research Project
- Consent form for Participants with Dementia
- Information Sheet for Informal and Formal Carer Participants
- Recruitment Letter for Informal and Formal Carer Participants
- Consent form for Informal and Formal Carer Participants
- Sample Letter to Personal Consultee
- Information Sheet for Personal Consultee
- Personal Consultee Declaration
- Baseline Information for Self-Identity in Dementia Research Study
- Barthel ADL Index

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v.1 May 2012

Participant Letter Code and Number:		

Project Procedural Checklist:

Research Stage	Date Completed	Signature
Patient Information Leaflet		
MCA Assessment and Checklist		
Participant with Dementia Consent Form		
Informal/Formal Participant Recruitment Letter		
Informal/Formal Participant Information Sheet		
Informal/Formal Participant Consent Form		
Personal Consultee Letter		
Personal Consultee Decision Form		
Personal Consultee Declaration Form		
Consultant Psychiatrist Notification Letter		
Baseline Information Form		
Patient MMSE		
Patient Barthel ADL Index		
SIQ Individual with Dementia		
SIQ Informal Carer Participant		
SIQ Formal Carer Participant		

Additional Information/Comments:

YOUR LIFE STORY...

My project aims to ask people in hospital about their life story, and I would like to invite you to take part. It will involve you answering questions about:

- Your Life
- Family
- Job
- Hobbies
- Likes/Dislikes

Your family   and nurse   will be asked the same questions.

This is to find out information about you which can help us understand you and your life story
This will contribute to the treatment the hospital provides, now and your future care.

If you want to talk to someone about the project and are happy to take part please speak to
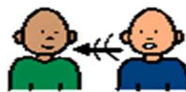
Aileen Murray. Senior Nurse

If you do not want to take part just let the nurses know

Many thanks for your time
in reading this.

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Participant Letter Code and Number:		

Mental Capacity Assessment for Consent to Participate in Proposed Research Project

Checklist for researchers to decide whether a prospective participant has the capacity to consent to their participation	
Section A: Enabling Capacity: Has every effort to enable a prospective participant to make the decision themselves to participate or refuse? Has language and methods of communication that the person is most likely to understand been used? Has the person has sufficient time to think about the project? Has the person spoken to others who could help explain the project?	
If NO to any item in Section A, to revisit enabling decision making. **If YES to all items in Section A, continue.**	
Section B: Diagnostic Assessment: Is there evidence to demonstrate impairment of mind or brain? Is there evidence to demonstrate that this is temporary, fluctuating or permanent? Is there evidence to demonstrate that the impairment affects the ability to decide about their participation in research?	
If NO to any item in Section B, to refer to researcher. **If YES to all items in Section B, continue.**	
Section C: Functional Assessment: Does the person understand that they can consent or refuse to participate in research? Does the person understand what the research is about? Does the person understand and weigh-up the benefits and risks of agreeing or refusing to take part? Has the person communicated their decision to you in any way?	
If YES to any item in Section C, revisit enabling decision making. **If NO to the first three items in Section C the person DOES NOT have the capacity to consent to or to refuse to take part in the research project.**	
Checklist completed by (signature): Print Name: Date:	

FURTHER COMMENTS/OUTCOMES OF CAPACITY FOR CONSENT TO RESEARCH PARTICIPATION ASSESSMENT FROM SECTIONS A, B AND C.

v.1 May 2012

Participant Letter Code and Number:		

Consent form for Participants with Dementia:

The research project will require approximately 20-30 minutes for the completion of the Self-Identity Questionnaire as detailed in the accompanied information sheet.

In accepting to participate in this research project it must be stressed that:

1. All data collected will be confidential; anonymity will be strictly maintained using pseudonyms or paraphrasing; and any and all data tapes and files will be erased at the completion of the study;

2. You may refuse to participate or may withdraw at any time from the research project without prejudice even if you sign this letter of consent. This includes for specific questions. You will be asked if any responses provided up to that point could be still be used as per the purposes of this study (see confidentiality above).

3. At any stage of your involvement you may request clarification on any issue regarding the project;

4. This study will not involve any risk of any kind whatsoever to you.

………………………………………………………………………………………………

Please sign the form below and return it to the researcher prior to completion of the questionnaire:

I, (PRINT) ………………………………………………., have read the research study recruitment letter, information sheet provided and consent form and have had the opportunity to discuss in full the nature of this project with the researcher.

I understand that this research component will be completed as unobtrusively as possible and in consultation with me. I give my consent to participate in this project and acknowledge receipt of a copy of this document.

Participant signature:………………………………………………………….....Date:

Researcher signature:………………………………………………………………Date:

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Information Sheet for Informal and Formal Carer Participants:

What is the project about?

In the United Kingdom there are currently 750,000 people with dementia and the impact that this illness has on the individual and carers is a significant one. Throughout the journey of the illness, there are unpredictable difficulties which may necessitate admission to hospital for assessment, treatment and support for all involved. The individual has been taken from a home that is familiar, safe and provides security through continuity (environment, surroundings and people) to a busy ward environment that can cause anxiety and distress.

The Self-Identity in Dementia Questionnaire is a systematic method for the assessment of self-identity in dementia. The Self-Identity Questionnaire (SIQ) explores four domains of identity: occupation, family, leisure and personal attributes from a multi-informant perspective (the individual with dementia, the informal carer and staff member or formal carer).

By ensuring that the patient's life history is documented from the three participant groups, a persons' self- identity could be preserved. The Self-Identity in Dementia Questionnaire is a tool which can ensure that this vital information is gained. We hope that the questionnaire results will benefit patients by improving the experience of hospitalisation and help us better understand ways of treating and supporting those with dementia.

Study aims:

• To determine the self-identity roles that people with dementia identify with.

• To establish the strength of the roles that people with dementia identify with.

• To explore the extent of agreement between the person, informal carer and staff related to the areas of self-identity.

• To identify the factors, if any, which might influence changes in self-identity whilst admitted to an acute psychiatric hospital.

Recruitment of participants:

The recruitment of participants for this study requires the agreement of all three participant groups for the SIQ information to be gathered. All patients admitted to the acute psychiatric assessment ward with a confirmed diagnosis of dementia will be invited to take part. However, patients will need to be (i) medically stable (ii) able to understand and speak English and (iii) for whom consent can be obtained. If you are an informal carer you may be approached by the researcher to be a Personal Consultee if the individual with dementia is unable to consent for themselves. Patients experiencing severe behavioural or psychological difficulties upon admission to the ward that pose a significant risk to him or her-self, informal carer, nursing staff or researcher will be excluded.

What participants are required to do:

The study will involve you taking 20-30 minutes of your time to complete a questionnaire (the Self-Identity in Dementia Questionnaire, or SIQ) related to your relative or the person you are caring for with dementia. It will focus on their family life, occupation, leisure pursuits, and personal attributes. It will ask you to rate the importance of these aspects in the past and present, it will go on to ask specific questions as to how your relative's identity can be preserved.

Potential risks or hazards related to the research:

The researcher does not foresee any risks or hazards posed towards informal or formal carers through completing the SIQ. If your participation in the study causes any discomfort or distress due to the content of the questionnaire at any time, you can withdraw at any time (see consent section below).

Confidentiality:

Please be assured that your identity will be kept strictly confidential by a coding system for the questionnaires and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study. Any and all data records kept on the researcher's computer hard disk will be password protected and accessed only by them. Please note that any and all quotes drawn from these questionnaires for the purposes of publication and/or seeking further research funding will be kept anonymous by using pseudonyms. In addition to the above protection, final reports and/or papers will be submitted to you for your review to ensure the protection of your identity. All paperwork relating to the study will be destroyed by shredding upon completion of the study.

Remuneration/Compensation:

Please note that there will be no remuneration or compensation for participation in this research project.

Contact for information about the study:

If you have any questions regarding the project and/or your involvement in it, please feel free to contact (NAME OF RESEARCH NURSE, STUDY SITE AND CONTACT DETAILS HERE)

Contact for concerns or complaints about the research:

If you have any concerns about your treatment or rights as a research participant, you may contact the local Research Ethics Group or NHS Complaints 0800 0132319.

If you would like a copy of the Executive Summary of the research study upon completion, please let the researcher know and provide a forwarding e-mail or home address.

Many thanks for taking the time to read this information.

v.1 May 2012

v.1 May 2012

Participant Letter Code and Number:		

Recruitment Letter for Informal and Formal Carer Participants

Date:

Dear Name,

Older Persons Mental Health services are collaborating with (NAME OF RESEARCH NURSE HERE) and the University of Portsmouth in a research project. The project is focussing on the preservation of self-identity in people with dementia when admitted to hospital.

We are letting informal carers of our service and formal carers such as our Registered Nurses know about this research project in case they would like to participate.

In the United Kingdom there are currently 750,000 people with dementia and the impact that this illness has on the individual and carers is a significant one. Throughout the journey of the illness, there are unpredictable difficulties which may necessitate admission to hospital for assessment, treatment and support for all involved. The individual has been taken from a home that is familiar, safe and provides security through continuity (environment, surroundings and people) to a busy ward environment that can cause anxiety and distress. By ensuring that the nursing staff get to know a patient, life history work focussing on a persons' self- identity comfort and continuity of care could be implemented.

The Self-Identity in Dementia Questionnaire (SIQ) is a tool which can ensure that this vital information is gained. We hope that the questionnaire results will benefit patients by improving the experience of hospitalisation and help us better understand ways of treating and supporting those with dementia.

If you do choose to participate, the study will involve you taking 20-30 minutes of your time to complete a questionnaire related to your relative or who you care for with dementia. It will focus on their family life, occupation, leisure pursuits, and personal attributes. It will ask you to rate the importance of these aspects in the past and present, it will go on to ask specific questions as to how your relative's identity can be preserved.

Please contact the study coordinator (NAME OF RESEARCH NURSE AND CONTACT DETAILS HERE) if you would like to learn more about the study. Your participation is completely voluntary. Whether you participate or not will have no effect on the care your relative receives here at (STUDY SITE HERE) or your job role. If you don't wish to participate or hear any more about the study, please let the nursing staff know as soon as possible following receipt of this letter.

If you have any questions, please contact me on the above number. Thank you in advance for considering this request, Yours sincerely, (RESEARCH NURSE HERE)

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v.1 May 2012

Participant Letter Code and Number:		

Consent form for Informal and Formal Carer Participants:

The research will involve answering the questionnaire for participants. The research project will require approximately 20-30 minutes for the completion of the Self-Identity Questionnaire as detailed in the accompanied information sheet.

In accepting to participate in this research project it must be stressed that:

1. All data collected will be confidential; anonymity will be strictly maintained using pseudonyms or paraphrasing; and any and all data tapes and files will be erased at the completion of the study;

2. You may refuse to participate or may withdraw at any time from the research project without prejudice even if you sign this letter of consent. This includes for specific questions. You will be asked if any responses provided up to that point could be still be used as per the purposes of this study (see confidentiality above).

3. At any stage of your involvement you may request clarification on any issue regarding the project;

4. This study will not involve any risk of any kind whatsoever to you.

………………………………………………………………………………………………

Please sign the form below and return it to the researcher prior to completion of the questionnaire:

I, (PRINT) ……………………………………………………, have read the research study recruitment letter, information sheet provided and consent form and have had the opportunity to discuss in full the nature of this project with the researcher.

I understand that this research component will be completed as unobtrusively as possible and in consultation with me. I give my consent to participate in this project and acknowledge receipt of a copy of this document.

Participant signature:…………………………………………………………….....Date:

Researcher signature:…………………………………………………………………Date

v.1 May 2012

Participant Letter Code and Number:		

Sample Letter to Personal Consultee

Date:

Dear Name,

Older Persons Mental Health services are collaborating with (NAME OF RESEARCH NURSE AND STUDY SITE) and the University of Portsmouth in a research project. The project is focussing on the preservation of self-identity in people with dementia when admitted to hospital.

An important aspect of the research project is that all participants have the choice about whether to volunteer or to refuse to take part. However some of the patients may not have the capacity to consent because of a condition or illness they have that affects how they make some decisions.

You have been approached as you are a partner, relative or friend of a patients' of this service. The researcher would like to discuss with you your views about whether ……………….. may wish to participate in the research.

I attach some information about the project and ways in which you can help.

Please have a look at the form and return to (NAME OF RESEARCH NURSE HERE) using the stamped addressed envelope. If you have any queries, please contact the above named person at (CONTACT DETAILS HERE).

Thank you for your interest in the project and taking time to read the information,

Yours sincerely,

(NAME OF RESEARCH NURSE HERE).

Participant Letter Code and Number:		

Decision from Personal Consultee

Decision from Personal Consultee	Choice and signature of Personal Consultee
I think that my partner, friend or relative may NOT like to take part in the project	Signed: Date:
I think my partner, friend or relative may be interested in taking part and I would like to discuss this with the researcher. I agree to being contacted further about the project.	Signed: Date:
I think my partner, friend or relative may like to take part in the project – but I do not wish to be consulted. I do not agree to being contacted further about the project.	Signed: Date:

Thank you for completing the form. Please send in the stamped addressed envelope or hand into staff on the ward.

Information Sheet for Personal Consultees.

What is the project about?

In the United Kingdom there are currently 750,000 people with dementia and the impact that this illness has on the individual and carers is a significant one. Throughout the journey of the illness, there are unpredictable difficulties which may necessitate admission to hospital for assessment, treatment and support for all involved. The individual has been taken from a home that is familiar, safe and provides security through continuity (environment, surroundings and people) to a busy ward environment that can cause anxiety and distress.

The Self-Identity in Dementia Questionnaire is a systematic method for the assessment of self-identity in dementia. The Self-Identity Questionnaire (SIQ) explores four domains of identity: occupation, family, leisure and personal attributes from a multi-informant perspective (the individual with dementia, the informal carer and staff member or formal carer).

By ensuring that the patient's life history is documented from the three participant groups, it is proposed that a persons' self- identity can be preserved. The Self-Identity in Dementia Questionnaire is a tool which can ensure that this vital information is gained. We hope that the questionnaire results will benefit patients by improving the experience of hospitalisation and help us better understand ways of treating and supporting those with dementia.

Study aims:

• To determine the self-identity roles that people with dementia identify with.

• To establish the strength of the roles that people with dementia identify with.

• To explore the extent of agreement between the person, informal carer and staff related to the areas of self-identity.

• To identify the factors, if any, which might influence changes in self-identity whilst admitted to an acute psychiatric hospital.

Recruitment of participants:

The recruitment of participants for this study requires the agreement of all three participant groups for the SIQ information to be gathered. All patients admitted to the acute psychiatric assessment ward with a confirmed diagnosis of dementia will be invited to take part. However, patients will need to be (i) medically stable (ii) able to understand and speak English and (iii) for whom consent can be obtained. If you are an informal carer you may be approached by the researcher to be a Personal Consultee if the individual with dementia is assessed to lack the capacity to consent for themselves.

Patients experiencing severe behavioural or psychological difficulties upon admission to the ward that pose a significant risk to him or her-self, informal carer, nursing staff or researcher will be excluded.

What participants are required to do:

The study will involve each participant group taking 20-30 minutes to complete a questionnaire (the Self-Identity in Dementia Questionnaire, or SIQ) related to the individual with dementia. It will focus on their family life, occupation, leisure pursuits, and personal attributes. It will ask them to rate the importance of these aspects in the past and present, it will go on to ask specific questions as to how the individual's identity can be preserved.

Potential risks or hazards related to the research:

The researcher does not foresee any risks or hazards posed towards any participant through completing the questionnaire. If your relative's participation in the study causes any discomfort or distress due to the content of the questionnaire at any time, you can withdraw at any time (see consent section below).

Confidentiality:

Please be assured that your identity will be kept strictly confidential by a coding system for the questionnaires and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study. Any and all data records kept on the researcher's computer hard disk will be password protected and accessed only by them. Please note that any and all quotes drawn from these questionnaires for the purposes of publication and/or seeking further research funding will be kept anonymous by using pseudonyms. In addition to the above protection, final reports and/or papers will be submitted to you for your review to ensure the protection of your identity. All paperwork relating to the study will be destroyed by shredding upon completion of the study.

Remuneration/Compensation:

Please note that there will be no remuneration or compensation for participation in this research project.

Contact for information about the study:

If you have any questions regarding the project and/or your involvement in it, please feel free to contact (NAME OF RESEARCH NURSE, STUDY SITE AND CONTACT DETAILS HERE).

Contact for concerns or complaints about the research:

If you have any concerns about your treatment or rights as a research subject, you may contact the local Research Ethics Group or NHS Complaints 0800 0132319.

If you would like a copy of the Executive Summary of the research study upon completion, please let the researcher know and provide a forwarding e-mail or home address.

Many thanks for taking the time to read this information.

Participant Letter Code and Number:		

Personal Consultee Declaration:

Declarations:	Initials of Personal Consultee following confirmation/understanding of the following statements:
I confirm that I have read and understood the Information for Consultees for the study.	
I confirm that I have had time and opportunity to ask questions about the study or my role a Personal Consultee.	
I understand the purpose of the project and what the participants (my partner, friend or relative's) involvement would be, in my opinion they would not object to taking part in the study.	
I understand that participation in the project is voluntary and that my partner, friend or relative would be withdrawn of they do not wish to continue participating and without giving reason.	
In understand that my partner, friend or relative were withdrawn from the project this would not affect in any way the care or treatment they receive or affect their legal rights.	
I understand that my partner, friend or relative's Consultant Psychiatrist will be informed about their involvement in the study.	

Name of Consultee:	Date:	Signature:
Name of person who has discussed the study and provided me with information:	Date:	Signature:
Researcher:	Date:	Signature:

When completed, one copy to be retained in healthcare record, one copy for Personal Consultee and one copy for the researcher.

v.1 May 2012

BASELINE INFORMATION FOR SELF-IDENTITY

IN DEMENTIA RESEARCH STUDY.

PARTICIPANT IDENTIFICATION LETTER AND NO:		
GENDER:		
DATE OF ADMISSION TO WARD:		
TYPE OF ADMISSION:	INFORMAL	
	SECTION 2 OF MENTAL HEALTH ACT	
	SECTION 3 OF MENTAL HEALTH ACT	
	OTHER	
SOURCE OF ADMISSION:	OWN HOME	
	RESIDENTIAL HOME	
	NURSING HOME	
	VIA GENERALHOSPITAL	
	OTHER (PLEASE SPECIFY)	
REASON FOR ADMISSION:	(OUTCOME OF ASSESSMENT OF CAPACITY TO CONSENT FOR ADMISSION TO HOSPITAL BY MEDICAL TEAM – YES / NO)	
MENTAL HEALTH DIAGNOSIS: (INCLUDE MMSE SCORE)		
PHYSICAL HEALTH HISTORY: (INCLUDE BARTHEL ADL SCORE)		
MEDICATION REGIME ON ADMISSION TO HOSPITAL:		
ANY OTHER INFORMATION:		

The Barthel ADL Index	Participant Letter Code and Number:

DATES OF ASSESSMENTS								

Bowels:
0 = Incontinent
1 = Occasional accident
2 = Continent

Bladder:
0 = Incontinent or catheterised & unable to manage
1 = Occasional accident (max 1 per 24 hours)
2 = Continent (for over 7 days)

Grooming:
0 = Needs help
1 = Independent, face/hair/teeth/ shaving

Toilet:
0 = Dependent
1 = Needs help but can do something
2 = Independent

Feeding:
0 = Unable
1 = Needs help cutting, spreading butter etc
2 = Independent

Transfer:
0 = Unable
1 = Major help (1-2 people, physical)
2 = Minor help (verbal or physical)
3 = Independent (but may use aid eg stick)

Mobility:

0 = Unable

1 = Wheelchair independent, including corners etc

2 = Walks with help of one person (verbal or physical)

3 = Independent

Dressing:

0 = Dependent

1 = Needs help but can do half unaided

2 = Independent

Stairs:

0 = Unable

1 = Needs help (verbal, physical, carrying aid)

2 = Independent, up and down

Bathing:

0 = Dependent

1 = Independent

Total:

Signature of Nurse:

Appendix 3: Adapted Self-Identity in Dementia Questionnaires;

(i)　　Adapted Self-Identity in Dementia Questionnaire

Individual with Dementia

(ii)　　Adapted Self-Identity in Dementia Questionnaire

Informal Carers

(iii)　　Adapted Self-Identity in Dementia Questionnaire

Formal Carers

Self-Identity in Dementia Questionnaire (SIQ)

Dear Participant,

Older Persons Mental Health services are collaborating with (NAME OF RESEARCH NURSE AND STUDY SITE HERE) and the University of Portsmouth in a research project focussing on the preservation of self-identity in people with dementia when admitted to hospital.

You were chosen to be part of the project due to currently being in hospital and have given consideration to consent to be part of this project.

This questionnaire will collect information about you and will contribute to your care and treatment whilst in hospital.

Please answer the questions is as much detail as possible. The researcher will be able to help you read and answer the questions if required.

The overall results from the project will be used to improve the care pathway for older people who require hospital treatment within Older Person Mental Health Services.

Many thanks for your time, and if you have any queries, please contact (NAME OF RESEARCH NURSE AND CONTACT DETAILS HERE).

Participant Name and Code:

Date:

Inpatient area:

SECTION A - JOB, OCCUPATION OR PROFESSION

Q1. What was your main job, occupation or profession? Please tick one, if there were several, choose the most important.

Homemaker / Housewife		Accountant	
Engineer		Teacher	
Military personnel		Architect	
Lawyer		Security / Law enforcement / Police	
Nurse		Medical doctor	
Sales Person / Shop Assistant		Scientist	
Clerk/Secretary		Factory Worker/Manufacturing	
Farmer		Professor	
Owner of Business / Self-employed		Had none / Unemployed	
Artist		Do not know	
Construction worker/ Builder		Other – Please specify	

Q2. How important is this job, occupation or profession to you today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q3. How important was this job/occupation to you in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

---

SECTION B - FAMILY RELATIONSHIPS

	Yes	No	Do not remember
Q1. Have you ever been married?			
Q2. Is your husband/wife alive?			
Q3. Are you divorced?			
Q4. Do you have children?			
Q5. Are your children alive?			

Q6. Which family relationship was most important for you?

Being a husband or wife		Being a son/ daughter-in-law	
Being a parent to children		Being a grandparent to his/her grandchildren	
Being a son/daughter to your parents		Do not remember	
Being a friend		Did not have any family relationships	
Being a sister/brother		Other – Please Specify	

Q7. How important was this relationship to you in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q8. How important is this relationship to you today?

Not at all important	Slightly important	Moderately important	Important	Very important

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SECTION C - HOBBIES AND ACTIVITIES

Q1. What are some of your favourite things to do (other than work)?

Reading/studying		Writing		Woodwork	
Gardening		Socialising/spending time with friends		Telling jokes/stories	
Painting		Cards		Religious activities	
Helping others / Voluntary work		Word games/puzzles		Physical activities	
Travelling		Collecting (stamps, books etc.)		Eating/ Tasting food	
Watching TV, videos or films		Crafts (sewing knitting etc.)		Trips outside / Days out	
Cooking		Caring for pets		Not relevant, never had leisure time	
Discussing politics / Current events		Listening to or playing music		Do not remember	
Comments					

Q2. How important were these hobbies and activities to you in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q3. How important are these hobbies and activities to you today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. What do you like doing here?

Reading/studying		Writing		Watching others	
Gardening		Socialising/spending time with friends		Likes to do nothing	
Painting		Listening to stories		Collecting (stamps books etc.)	
Volunteering		Looking at pictures of family or friends/using photos for the past		Crafts (sewing knitting etc.)	
Talking about the past		Cards, word games/crossword puzzles		Listening to or playing music	
Watching TV, videos or films		Telling jokes/stories		Speaking about family and friends	
Cooking		Physical activities		Refreshments/meals	
Caring for pets		Trips outside / Days out		Do not like anything	
Woodwork		Religious activities		Do not know	
Discussing politics		Discussion groups			
Comments					

Q5.What do you like doing but cannot do here?

PERSONAL ACHIEVEMENTS, ATTRIBUTES AND TRAITS

Q1. In which things are you especially proud? (Could be personal achievements, special traits, special past)

Beauty/fitness		Knowledge/intelligence/wisdom		Selflessness/self-sacrifice	
Artistic achievements		Birthplace		Honesty/fairness/ trustworthiness	
Family history and heritage		Traits (distinguishing characteristics)		Past experience (e.g. holocaust)	
Financial assets, economic achievements		Service/ contribution to country		No achievements or attributes	
Success of a family member		Friends/social achievements/popularity		Do not remember	
Devotion to work		Surviving ability		Other – Please Specify	
Devotion to family		Academic achievements			

Q2. How important were these achievements, attributes and traits to you in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q3. How important are these achievements, attributes and traits to you today?

Not at all important	Slightly important	Moderately important	Important	Very important

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ADDITIONAL QUESTIONS

Q1. How would you like the staff to refer to you?

By your first name		Mr or Mrs	
By your nickname		Do not know	
Doctor		Other – Please Specify	
Professor			

Thank you for your help.

Self-Identity in Dementia Questionnaire (SIQ)

Dear Participant,

Older Persons Mental Health services are collaborating with (NAME OF RESEARCH NURSE AND CONTACT DETAILS HERE) and the University of Portsmouth in a research project focussing on the preservation of self-identity in people with dementia when admitted to hospital. Self-identity refers to a person's awareness of themselves as a person and a sense of belonging as a social individual.

You were chosen to be part of the project due to currently being a relative or carer of an individual with dementia in hospital and have given consent to be part of this project.

This questionnaire will collect information about your relative with dementia and will contribute to your care and treatment whilst in hospital.

Please answer the questions is as much detail as possible. I have included a self-addressed envelope to return the questionnaire, please do so as so as possible.

The overall results from the project will be used to improve the care pathway for older people who require hospital treatment within Older Person Mental Health Services.

Many thanks for your time, and if you have any queries, please contact (NAME OF RESEARCH NURSE AND CONTACT DETAILS HERE).

Participant Name and Code:

Completing the Questionnaire about (Relative Name):

Relationship to person with dementia:

Date:

Inpatient area:

SECTION A - JOB, OCCUPATION OR PROFESSION

Q1. What level of education did your relative attain?

Completed part of elementary school		Bachelor's degree	
Completed elementary school		Graduate studies	
Completed part of secondary school		Masters/PhD	
Completed part of undergraduate school		Other – Please specify	

Q2. What was your relatives' main job, occupation or profession? Please tick one, if there were several choose the most meaningful.

Homemaker / Housewife		Accountant	
Engineer		Teacher	
Military personnel		Architect	
Lawyer		Security / Law enforcement / Police	
Nurse		Medical doctor	
Sales Person / Shop Assistant		Scientist	
Clerk/Secretary		Factory Worker/Manufacturing	
Farmer		Professor	
Owner of Business / Self-employed		Had none / Unemployed	
Artist		Do not know	
Construction worker / Builder		Other – Please specify	

Q3. For how many years did your relative work at this job, occupation or profession?

Specify Years		Do not know	
Most of adult life		Not relevant	

Q4. In the years that your relative worked in this job, occupation or profession how many hours a day did s/he dedicate to it?

Full time		Do not know	
Part time		Not relevant	

Q5. How important was this job, occupation or profession to your relative in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q6. How important is this job, occupation or profession to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q7. How often does s/he talk about this job, occupation or profession?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q8. How often does his/her behaviour show that this was his/her job, occupation or profession?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q9. In the years that your relative worked in this job, what was his/her attitude toward this job, occupation or profession?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

Q10. What is his/her attitude towards this job, occupation or profession today?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

SECTION B - FAMILY RELATIONSHIPS

Q1. Which family relationship do you feel is most important for your relative?

Being a husband or wife		Being a son/ daughter-in-law	
Being a parent to children		Being a grandparent to his/her grandchildren	
Being a son/daughter to his/her parents		Did not have any family relationships	
Being a friend		Do not know	
Being a sister/brother		Other – Please Specify	

Q2. How important is this relationship to him/her in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q3. How important is this relationship to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. How often does s/he talk about this relationship?

Not at all	Rarely	Several times a week	Every day or nearly everyday	Most of the time	Unable

Q5. How often does his/her behaviour show that this was his/her most important relationship?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q6. What do you feel is his/her attitude toward this relationship in the past?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

Q7. What do you feel is his/her attitude toward this relationship today?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

SECTION C - HOBBIES AND ACTIVITIES

Q1. What are his/her favourite hobbies and leisure activities?

Reading/studying		Writing		Woodwork	
Gardening		Socialising/spending time with friends		Telling jokes/stories	
Painting		Cards		Religious activities	
Helping others / Voluntary work		Word games/puzzles		Physical activities	
Travelling		Collecting (stamps, books etc.)		Eating/ Tasting food	
Watching TV, videos or films		Crafts (sewing knitting etc.)		Trips outside / Days out	
Cooking		Caring for pets		Not relevant, never had leisure time	
Discussing politics / Current events		Listening to or playing music		Do not remember	
Comments					

Q2. How important were these hobbies and activities to him/her in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q3. How important are these hobbies/activities to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. How often does s/he talk about these hobbies or activities?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q5. How often does his/her behaviour show that this was his/her hobby or activity?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q6. What was his/her attitude towards these hobbies or activities in the past?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

Q7. What was your relative's attitude towards these hobbies or activities today?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

PERSONAL ACHIEVEMENTS, ATTRIBUTES AND TRAITS

Q1. Of which personal achievement, special traits or attributes was your relative especially proud?

Beauty/fitness		Knowledge/intelligence/wisdom		Selflessness/self-sacrifice	
Artistic achievements		Birthplace		Honesty/fairness/ trustworthiness	
Family history and heritage		Traits (distinguishing characteristics)		Past experience (e.g. holocaust)	
Financial assets, economic achievements		Service/ contribution to country		No achievements or attributes	
Success of a family member		Friends/social achievements/popularity		Do not remember	
Devotion to work		Surviving ability		Other – Please Specify	
Devotion to family		Academic achievements			

Q2. How important were these achievements or traits to him/her in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q3. How important are these achievements or traits to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. How often does s/he talk about these achievements?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q5. How often does his/her behaviour show that this was his/her most important achievement, attribute or trait?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q6. What was his/her attitude towards these achievements or traits in the past?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

Q7. What was his/her attitude towards these achievements or traits today?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

QUESTIONS RELATED TO SELF-IDENTITY

Q1. Which family role/identity is most important for your relative now?

As a professional/housewife		Other	
As a family member or other social role		Has none	
As someone with a hobby/leisure activity		Do not know	
As someone with achievements/traits			

Q2. Does your relative have any identities or traits/occupations that are not based on/or were of minor importance in his/her past? If yes, please specify?

As a professional/housewife		Other	
As a family member or other social role		Has none	
As someone with a hobby/leisure activity		Do not know	
As someone with achievements/traits			

Q3. When did this change in identity occur?

Q4. If there were changes in identity, what change is the most important?

Q5. If s/he had a change in identity what was your reaction to this change?

Very relieved		Slightly painful	
Relieved		Painful	
Slightly relieved		Very painful	
indifferent			

Q6. What words, subjects or activities have a special effect on him/her (making him/her happier, more coherent, remember his/her identity)?

Listening to music		Recalling memories, talking about certain events on the past	
Socialising/spending time with friends		Talking about family or friends	
Watching movies/videos		Cards/games/crossword puzzles	
Trips outside the nursing home		Looking at pictures of family or friends	

Q7. What causes him/her to get especially angry, agitated or to behave differently than usual?

ADL activities such as eating/using the toilet		Frustration at disorientation to place	
Watching TV, news or movies		Maintaining attention to activity	
Dismissal time		Starting new activity	
Frustration during an activity		Other people's behaviour	
Structured/physical environment such as locked doors etc.		There is no consistency in events	
Does not get especially angry		I do not know	
Other – Please specify			

Q8. Is it possible, in your opinion, to enhance the feeling of self-identity?

Yes		No	
Somewhat/maybe		Do not know	

Q9. If enhancing the feeling of self-identity is possible, do you think this would contribute to your relative's sense of well-being?

Yes, it will contribute very much		No, it will cause some harm	
Yes, it will contribute somewhat		No, it will cause a lot of harm	
It will not make a difference		Do not know	

Q10. In which ways (such as certain activities, words or changing environment) could we, in your opinion enhance or cultivate the self-identity feelings of your relative?

Listening or playing music		Watching TV		Arts and crafts	
Socialising/spending time with friends		Writing		Reading/studying	
Watching movies/videos		Walking or other exercise		Discussing politics/current events	
Trips outside the nursing home		Eating, tasting food		Not relevant	
Recalling memories, talking about past events		Spending time with/caring for pets		Do not know	
Cards, games or crossword puzzles		Religious activities/topics		Bringing furnishings from home	
Talking about family or friends		Discussion groups		Other – Please specify	

Q11. What causes your relative to feel more who s/he is and what is important to him/her?

Family or friends visiting		Letters or cards from family or friends	
Going out of hospital		Other – Please specify	

Q12. Do you think that the way you see your relative is the same way the staff sees him/her in the subject of his/her self-identity?

The same		Totally different	
Somewhat different		Do not know	
Comments			

Q13. What identity does it seem that your relative would like to preserve?

As someone with a job/profession/housewife		As someone with achievements/unique traits	
As a family person		Do not know	
As someone with a hobby/leisure time activities		Other - Please specify	
Comments			

Q14. What kind of surroundings/environment does your relative prefer?

Quiet		Familiar environment	
Monotonous		New environment (places)	
Stimulating		Other – Please specify	

Q15. Is this a change from the past?

Yes		No	

Q16. By which name or title do you think the staff should refer to your relative?

By his/her first name		Professor	
By a nickname		Dr	
Mr or Mrs		Other – Please specify	

Thank you for your help.

Self-Identity in Dementia Questionnaire (SIQ)

Dear Participant,

Older Persons Mental Health services are collaborating with (NAME OF RESEARCH NURSE AND CONTACT DETAILS HERE) and the University of Portsmouth in a research project focussing on the preservation of self-identity in people with dementia when admitted to hospital. Self-identity refers to a person's awareness of themselves as a person and a sense of belonging as a social individual.

You were chosen to be part of the project due to currently being a Registered Nurse caring for an individual with dementia in hospital and have given consent to be part of this project.

This questionnaire will collect information about your relative with dementia and will contribute to your care and treatment whilst in hospital.

Please answer the questions is as much detail as possible. I have included a self-addressed envelope to return the questionnaire, please do so as so as possible.

The overall results from the project will be used to improve the care pathway for older people who require hospital treatment within Older Person Mental Health Services.

Many thanks for your time, and if you have any queries, please contact (NAME OF RESEARCH NURSE AND CONTACT DETAILS HERE).

Participant Name and Code:

Completing the Questionnaire about (Patient Name):

Date:

Inpatient area:

SECTION A - JOB, OCCUPATION OR PROFESSION

Q1. What was his/her job, occupation or profession? If there is more than one choose the most important.

Homemaker / Housewife		Accountant	
Engineer		Teacher	
Military personnel		Architect	
Lawyer		Scientist	
Nurse		Medical doctor	
Sales Person / Shop Assistant		Security / Law enforcement / Police	
Clerk/Secretary		Factory Worker/Manufacturing	
Farmer		Professor	
Owner of Business / Self-employed		Had none / Unemployed	
Artist		Do not know	
Construction worker / Builder		Other – Please specify	

Q2. Was this his/her main job, occupation or profession in the past?

Yes	
No	
Do not know	

Q3. In your opinion, how important is this job, occupation or profession to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. How often does s/he talk about this job, occupation or profession?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q5. How often does his/her behaviour show that this was his/her job, occupation or profession?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable
Please Specify:					

Q6. In your opinion, what is his/her attitude toward this job, occupation or profession?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

SECTION B - FAMILY RELATIONSHIPS

Q1. Which family relationship do you feel is most important for the individual with dementia?

Being a husband or wife		Being a son/ daughter-in-law	
Being a parent to children		Being a grandparent to his/her grandchildren	
Being a son/daughter to his/her parents		Did not have any family relationships	
Being a friend		Do not know	
Being a sister/brother		Other – Please Specify	

Q2. Was this his/her main relationship on the past?

Yes	
No	
Do not know	

Q3. How important was this relationship to him/her in the past?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. How often does s/he talk about this relationship?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q5. In your opinion, how important is this relationship to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q6. How often does his/her behaviour show that this was his/her most important relationship?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable
Please specify:					

Q6. In your opinion, what do you feel is his/her attitude toward this relationship?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

SECTION C - HOBBIES AND ACTIVITIES

Q1. What are his/her favourite hobbies and leisure activities?

Reading/studying		Writing		Woodwork	
Gardening		Socialising / spending time with friends		Telling jokes/stories	
Painting		Cards		Religious activities	
Helping others / Voluntary work		Word games/puzzles		Physical activities	
Travelling		Collecting (stamps, books etc.)		Eating/ Tasting food	
Watching TV, videos or films		Crafts (sewing knitting etc.)		Trips outside / Days out	
Cooking		Caring for pets		Not relevant, never had leisure time	
Discussing politics / Current events		Listening to or playing music		Do not remember	
Comments					

Q2. Were these his/her main hobbies or leisure activities in the past?

Yes	
No	
Do not know	

Q3. In your opinion, how important are these hobbies or activities to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. How often does s/he talk about these hobbies or activities?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q5. How often does his/her behaviour show that these were his/her hobbies or leisure activities?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable
Please specify:					

Q6. What was his/her attitude towards these hobbies or activities?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

Q7. What was your relative's attitude towards these hobbies or activities today?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

PERSONAL ACHIEVEMENTS, ATTRIBUTES AND TRAITS

Q1. Of which personal achievements, experiences or attributes are most important to the individual with dementia?

Beauty/fitness		Knowledge/intelligence/wisdom		Selflessness/self-sacrifice	
Artistic achievements		Birthplace		Honesty/fairness/ trustworthiness	
Family history and heritage		Traits (distinguishing characteristics)		Past experience (e.g. holocaust)	
Financial assets, economic achievements		Service/ contribution to country		No achievements or attributes	
Success of a family member		Friends/social achievements/popularity		Do not remember	
Devotion to work		Surviving ability		Other – Please Specify	
Devotion to family		Academic achievements			

Q2. Were these his/her main achievements, attributes or traits in the past?

Yes	
No	
Do not know	

Q3. In your opinion, how important are these achievements, attributes or traits to him/her today?

Not at all important	Slightly important	Moderately important	Important	Very important

Q4. How often does s/he talk about these achievements, attributes or traits?

Not at all	Rarely	Several times a week	Every day or nearly everyday	Most of the time	Unable

Q5. How often does his/her behaviour show that this was his/her most important achievement, attribute or trait?

Not at all	Rarely	Several times a week	Everyday or nearly everyday	Most of the time	Unable

Q7. What was his/her attitude towards these achievements, attributes or traits?

Positive		Indifferent	
Both positive and negative		Do not know	
Negative		Not relevant	

QUESTIONS RELATED TO SELF-IDENTITY

Q1. Which role or identity is most important for the individual with dementia now?

As a professional/housewife		Other	
As a family member or other social role		Has none	
As someone with a hobby/leisure activity		Do not know	
As someone with achievements/traits			

Q2. Which new identity does the individual with dementia have that is not based on his/her past? Or was of minor importance? If yes, please specify?

As a professional/housewife		Other	
As a family member or other social role		Has none	
As someone with a hobby/leisure activity		Do not know	
As someone with achievements / traits			
Please specify:			

Q4. Which identities does it seem to you that the individual with dementia would like to preserve?

As a professional/housewife		Other	
As a family member or other social role		Has none	
As someone with a hobby/leisure activity		Do not know	
As someone with achievements/traits			
Please specify:			

Q5. Which roles do other individuals on the ward see in the individual with dementia?

As a professional/housewife		Other	
As a family member or other social role		Has none	
As someone with a hobby/leisure activity		Do not know	
As someone with achievements/traits			
Please specify:			

Q6. Which words, subjects or activities have a special effect on the individual with dementia (making him/her happier, more coherent, remember his/her identity)?

Listening to music		Recalling memories, talking about certain events on the past	
Socialising/spending time with friends		Talking about family or friends	
Watching movies/videos		Cards, games or crossword puzzles	
Trips outside the nursing home		Looking at pictures of family or friends	

Q7. What causes him/her to get especially angry, agitated or to behave differently than usual?

ADL activities such as eating/using the toilet		Starting new activity	
Watching TV, news or movies		Maintaining attention to activity	
Dismissal time		Frustration at disorientation to place	
Frustration during an activity		Other people's behaviour	
Structured/physical environment such as locked doors etc		There is no consistency in events	
Does not get especially angry		I do not know	
Other – Please specify			

Q8. Is it possible, in your opinion, to enhance the feeling of self-identity in individuals with dementia?

Yes		No	
Somewhat/maybe		Do not know	

Q9. If enhancing the feeling of self-identity is possible, do you think this would contribute to the individual with dementia's sense of well-being?

Yes, it will contribute very much		No, it will cause some harm	
Yes, it will contribute somewhat		No, it will cause a lot of harm	
It will not make a difference		Do not know	

Q10. In which ways (such as certain activities, words or changing environment) could we, in your opinion enhance or cultivate the self-identity feelings of this individual with dementia?

Listening or playing music		Watching TV		Arts and crafts	
Socialising/spending time with friends		Writing		Reading/studying	
Watching movies/videos		Walking or other exercise		Discussing politics/current events	
Trips outside the nursing home		Eating, tasting food		Not relevant	
Recalling memories, talking about past events		Spending time with/caring for pets		Do not know	
Cards, games or crossword puzzles		Religious activities/topics		Bringing furnishings from home	
Talking about family or friends		Discussion groups		Other – Please specify	

Q11. Have there been changes in his/her feelings of self-identity over the course of his/her illness?

Yes	
No	
Do not know	
Specify identity changes:	

Q12. Do you think that the way you see the individual with dementia is the same way the family sees him/her in the subject of his/her self-identity?

The same		Totally different	
Somewhat different		Do not know	
Comments			

Q13. Do you have any other comments or suggestions concerning the self-identity of the individual with dementia?

Q14. Does the individual with dementia have a preference in surroundings or environment?

Quiet		Familiar environment	
Monotonous		New environment (places)	
Stimulating		Other – Please specify	

Q15. By which name/title do you think the staff should refer to the individual with dementia?

By his/her first name		Professor	
By a nickname		Dr	
Mr or Mrs		Other:	

Appendix 4: University of Portsmouth Form UPR16

Research Ethics Review Checklist

FORM UPR16

University of **Portsmouth**

Research Ethics Review Checklist

Please include this completed form as an appendix to your thesis (see the Postgraduate Research Student Handbook for more information

Postgraduate Research Student (PGRS) Information	Student ID:	031940
PGRS Name:	Aileen Murray	
Department:	School of Health Sciences and Social Work	**First Supervisor:** Dr Ann Dewey
Start Date: (or progression date for Prof Doc students)	**October 2008**	

Study Mode and Route:	Part-time	☒	MPhil	☐	MD	☐
	Full-time	☐	PhD	☐	Professional Doctorate	☒

Title of Thesis:	The extent by which self-identity dimensions can be ascertained in people with dementia admitted to an acute psychiatric hospital: a pilot study to determine feasibility and applicability of an adapted Self-Identity in Dementia Questionnaire
Thesis Word Count: (excluding ancillary data)	Approx 60,000

If you are unsure about any of the following, please contact the local representative on your Faculty Ethics Committee for advice. Please note that it is your responsibility to follow the University's Ethics Policy and any relevant University, academic or professional guidelines in the conduct of your study

Although the Ethics Committee may have given your study a favourable opinion, the final responsibility for the ethical conduct of this work lies with the researcher(s).

UKRIO Finished Research Checklist:		
(If you would like to know more about the checklist, please see your Faculty or Departmental Ethics Committee rep or see the online version of the full checklist at: http://www.ukrio.org/what-we-do/code-of-practice-for-research/)		
a) Have all of your research and findings been reported accurately, honestly and within a reasonable time frame?	YES ☒ NO ☐	
b) Have all contributions to knowledge been acknowledged?	YES ☒ NO ☐	
c) Have you complied with all agreements relating to intellectual property, publication and authorship?	YES ☒ NO ☐	

d) Has your research data been retained in a secure and accessible form and will it remain so for the required duration?	YES	☒
	NO	☐
e) Does your research comply with all legal, ethical, and contractual requirements?	YES	☒
	NO	☐

Candidate Statement:	
I have considered the ethical dimensions of the above named research project, and have successfully obtained the necessary ethical approval(s)	
Ethical review number(s) from Faculty Ethics Committee (or from NRES/SCREC):	12/SC/0401
If you have *not* submitted your work for ethical review, and/or you have answered 'No' to one or more of questions a) to e), please explain below why this is so:	
Signed (PGRS):	**Date:** October 2012

Chapter Nine - PUBLICATIONS FROM THE PROFESSIONAL DOCTORATE IN NURSING

Murray, A. (2011). The implementation of a self-administration of medication programmes within Older Persons Mental Health. *Journal of Psychiatric and Mental Health Nursing*, 18 (2), 113-21.

Murray, A. (2013). The mental capacity act and dementia research. *Nursing Older People*, 25 (3), 14-20.

Murray, A. (2014). The effect of dementia on patients, informal carers and nurses. *Nursing Older People*, 26 (5), 27-31.

The implementation of a self-administration of medication programmes within Older Persons Mental Health

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Senior Nurse, Older Persons Mental Health, Solent Health Care NHS Trust, Portsmouth, UK

Accessible summary

- An exploration of the concept of self-administration of medication and its applicability to Older Persons Mental Health (OPMH) services.
- Background to a project that was investigating how to introduce the self-administration of medication within OPMH services.
- Future directions of the self-administration of medication within OPMH.

Abstract

This paper aims to report on the literature related to self-medication programmes that contributed to the development of an Older Persons Mental Health (OPMH) specific pathway for a self-administration of medication (SAM) programme. The traditional methods used within mental health inpatient environments to administer medication are paternalistic and resonant of the medical approach to care. There is a need to investigate innovative methods in the management of depression in older adults that reflect an individualized, innovative approach to redress the power imbalance for patients. Electronic databases were searched using the search strategy of Hek *et al.* to identify key themes in the implementation of self-administration programmes. Seven themes emerged from the literature review: the structure of SAM, assessments and risks associated with SAM, patient education, SAM and medication adherence, the patients' perspective, advantages and barriers to SAM, and professional issues. These findings were then used as the foundation for a project to develop an OPMH specific pathway for the implementation of SAM. There is a distinct lack of implementation of SAM programmes across the UK, especially within mental health services. Older Persons Mental Health is ready for the implementation of change in medicines management for older adults. Self-administration of medication can ensure all the principles of NHS plan relating to individualized person-centred care are achieved. Nurses have the opportunity to actively contribute to this process, facilitating and empowering those in their care to be experts within their journey and take control of their illness.

Introduction

This paper intends to outline the preparatory work that was required to implement a self-administration of medication (SAM) programme within an Older Persons Mental Health (OPMH) Service. It will provide a background to the project including current issues related to depression in older adults, treatment options and outline the current medication administration practices within a functional assessment ward. This will provide clear rationale for the project. A brief literature review focusing on hospital-based SAM programmes will be provided, including an overview

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of key influential government documents that have guided the development of SAM. Its effectiveness, benefits, barriers and associated clinical issues will be highlighted. It will then introduce the reader to the Plan, Do, Study, Act (PDSA) cycle and how this can be effectively used for practice development projects such as the implementation of SAM within OPMH. Finally there will be a summary of the newly developed protocol for the SAM within OPMH, the planned implementation of the programme and discussion of additional work required.

Background

There is wide spread recognition that the population in the UK is ageing, with people over the age of 65 increasing from 15% in 1983 to 16% in 2008, an increase of 1.5 million older people (Department of Health 2009).

With age, there is an increase in health-related co-morbid conditions, and according to Vik *et al.* (2006) persons over 65 years of age consume a disproportionate number of prescribed medications. McGraw & Drennan (2004) quantify this by stating that in the UK, 4000 million of the NHS annual budget was spent on prescriptions for those over 60, with older people receiving more prescriptions per head when compared with younger people (Department of Health 2002). Because of the associated health-related outcomes and resource implications there has been an interest in improving medicines management for older people to address both physical (acute and chronic) health issues and mental health conditions such as dementia and depression.

Depression in older people is very common albeit under recognized and under treated because of complexities associated with diagnosis. Subsequently there are wide variations in prevalence rates, with figures for depressive symptoms and syndromes ranging from 8 to 20 per cent of older community residents (Gallo *et al.* 1993, Alexopoulos 1997) and 17 to 35 per cent of older primary care patients (Gurland *et al.* 1996). Precipitating factors for depression in late life include significant life events, bereavement, acute illness requiring hospitalization and financial crises, or stress-related factors such as retirement, declining health, being a carer or social isolation (Chew-Graham & Baldwin 2008).

The most recent National Institute of Clinical Excellence guidance on the assessment and management of depression was published in October 2009. They propose a stepped model of care where professional intervention is governed by severity and impact of depression, from mild to the most severe and complex of presentations, where there is risk of self-neglect and risk to life. These situations require hospital admission with high levels of psychiatric input,

psychosocial support, review of treatment options, including medication review in a specialist care environment (National Institute of Clinical Excellence 2008).

Identification of the issue

Upon admission to the functional assessment ward within OPMH, there is what Watson (2006, p. 935) describes as a 'ritual confiscation' of medication, where the nursing staff remove an individual's medication and store it in a locked medicine cupboard or trolley. Throughout the duration of the admission, medication is reviewed and antidepressant type changed or dose amounts changed. Other changes include times of daily administration and even the colour of tablet altered from what the person is used to and familiar with. Administration of this medication will be conducted by a Registered Nurse from a medication card, written by a ward doctor at times dictated by the ward routine and staff convenience. These processes unfortunately reflect the dominance of the 'medical model' within mental health practice, a term first coined by R.D. Laing (Beveridge 1998) in the early 1970s. There is a focus on psychiatric diagnosis, the 'disease', illness management and prognosis, with the balance of power firmly lying with the healthcare professional that 'manages' the individuals' care. Risk adverse practices prevail, with severe reluctance to relinquish control to the patient in areas such as medicines management. Fears for the maintenance of personal safety within the assessment unit continue to be the factors that perpetuate the lack of patient autonomy, decision-making or self-determination.

The dichotomy of autonomous self-management of illness versus paternalistic nursing practices is embedded in current care practices, and the incongruity of approach is stressed during the planning stages of discharge. The patient will go on home leave where they are given their medication to be self-administered, unsupervised for the duration of the leave. On their return to the ward this is once more taken away from the individual to be locked away, despite managing this aspect of their care whilst at home. This causes mixed messages for the patient as well as mental health nurses working within this environment, as current philosophy and teaching regarding person-centred practices does not reflect what is actually happening in practice.

Several questions arose from observing this practice:
- Could we challenge the current care practices, increase care collaboration to make treatment and management of depressive illness more inclusive for older people within our care?
- Could we introduce a SAM programme for older people within the functional mental health assessment ward within OPMH?

- Could we implement an approach that facilitates the patients' recovery from severe mental illness, resonant of the recovery agenda?

Method

A literature search was conducted to identify appropriate data in a methodical manner, using the search strategy of Hek *et al.* (2000). This seven-stage model provided guidance on fundamental aspects of the literature review process from initiating a search to thematically reviewing the data.

- Stage 1 – Main computerized database search;
- Stage 2 – Narrow and more focused manual selection;
- Stage 3 – Supplementary searching;
- Stage 4 – Management and acquisition of relevant literature;
- Stage 5 – Quality appraisal of literature;
- Stage 6 – Literature review saturation;
- Stage 7 – Thematic review of the literature.

A search planning form allowed the identification of key concepts and words, synonyms and thesaurus terms to facilitate the direction of the search strategy. Through the use of 'Boolean operators' (self-administration, self-administration hospital, self-medication, self-medication programmes, drug self-administration) data were reviewed. Results were then re-searched with the terms 'mental health' and 'older people' to review articles specific to this cohort. Inclusion criteria were: work published within the past 15 years to ensure contemporary work, reflecting recent Government policy and guidance relating to health and social needs of older people, descriptive information about SAM and evaluative papers of methods of implementing self-administration programmes, where possible specifically relating to people over the age of 60. The resources chosen were Medline, CINAHL and British Nursing Index and EMBASE, accessed through the National Library for Health. Appraisal of the chosen papers was conducted by the author using the Critical Appraisal Skills Programme tools, ensuring that the research used in the article was rigorous and provided appropriate evidence to support the research (see http://www.phru.nhs.uk/pages/phd/resources.htm).

Literature review results

In 2001, with the publication of the *National Service Framework for Older People: Medicines and Older People* (Department of Health 2001) and *A Spoonful of Sugar* (Audit Commission 2001) there was a strategic policy focusing on improving services related to medicines man-

agement for older people. These two documents strongly recommended changes to traditional ways of working, stressing the need for quality improvements in medicines management, including the implementation of self-administration programmes within the hospital setting. However, despite guidance and research endorsing its realization, Wright *et al.* (2006) stated that less than half of hospitals within the UK had acted upon this recommendation. The lack of progress in working towards the goals of patient-focused improvements and quality-driven care as outlined in the NHS Plan (Department of Health 2000) galvanized policy development, and the Darzi Report (2008) once again emphasized the need to focus on the patient experience, which in turn would provide insight to the provision of high-quality individualized care.

Definition of SAM programmes

Medicine management strategies to provide this individualized care would include SAM programmes. However, there appears to be ambiguity relating to a precise definition of SAM, as many articles did not offer one, merely a description. One offered by Davis (1991) begins by stating that the patient is 'allowed' to retain all prescribed drugs immediately reinforcing the paternalistic nature of health care identified within current nursing practices. However, a useful definition is provided by Ruppar *et al.* (2008, p. 137), who stated 'self administration programmes consist of interventions to train individuals to correctly and reliably take their own medications'. However, there is agreement throughout research into SAM as to its underpinning philosophy and principles. These focus on promoting independence (Bird & Hassall 1993), reinforcing ideals related to the 'expert patient' programme (NHS Plan, Department of Health 2000) empowerment and partnership working (Commission for Health Improvement 2009), assisting rehabilitation and recovery processes (National Prescribing Centre 2008), enhancing patient autonomy (Manias *et al.* 2004), and implementing collaborative care within the management of chronic disease (Bodenheimer *et al.* 2002).

The design of a SAM programme varies, but generally consists of a patient inclusion and exclusion criteria based upon a thorough assessment of mental and physical health, implementation of education and information sharing and consent processes. A graduated or staged approach is used where the patient progresses from supervised medication administration to having increased responsibility and independence relating to administration of medications. However, Wright *et al.* (2006) stated that level progression can vary in length of time and decision-making relating to progression varies as to who initiates it and implements the next level. There are also variations in expected completion

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date, with some programmes aiming for completion pre-discharge but others with self-administration abilities the deciding factor postponing discharge as within rehabilitative care environments (Resnick *et al*. 1996).

Assessment and risk associated with SAM programmes

Appropriateness for inclusion in SAM was a theme highlighted by Manias *et al*. (2004), and a question of competence was raised; interestingly they felt that depressive symptoms were an indicator of incompetence. No further references were made to this negative perspective, despite it having a potentially significant impact on the patients within that care setting.

Whether it is an issue of competence to participate or risks associated with SAM, the literature provides different perspectives. Wright *et al*. (2006) claims that often risks are associated with patient safety, professional accountability and resources concerns, all of which have been identified as potential barriers to its implementation.

Maidment *et al*. (2008) proposed that medication errors are more common in older people because of the complexities associated with co-morbidities, and Swanlund *et al*. (2008) stated that as many as 28% of hospital admissions involving older adults are medication related. Formby (2008) provided persuasive argument for the use of SAM as a method of reducing these errors.

The Audit Commission (2001) recognized that SAM programmes do have an element of risk, but through risk management strategies, elements of risk can be reduced. Positive risk taking was embraced by Fuller & Watson (2005), who developed a risk assessment instrument that specifically focused on the potential hazards associated with SAM in older people. The risk assessment criteria included difficulties in self-management of medication, numbers of prescribed medicines, types of medications prescribed, medicines management issues, sensory factors, social circumstances, mental health, physical condition and overall attitudes towards medication. The screening tool was demonstrated to reliably identify individuals who were likely to have difficulties taking medication safely, thus allowing for further in-depth reviews, educational focus and input to overcome any identified areas of difficulty.

Education and SAM programmes

Self-administration of medication programmes contain a variety of education and information provision with different approaches and formats, from simple verbal instruction, written information only, discussion and written combined, or detailed structured information on medication purpose, correct use, side effects, interactions, storage and safety aspects, as well as compliance aids, diaries and record sheets (Wright *et al*. 2006).

The role of education as part of SAM has been studied with variable results.

Parker (1997) evaluated the effectiveness of a SAM programme with older adults with physical illness through questionnaires, and despite being a small-scale review, 60% improved their knowledge of medication. Similarly, Shen *et al*. (2006) conducted a study of how to improve older adults knowledge and understanding relating to prescribed medication. An individualized training programme run by Registered Nurses consisted of half-hour sessions over 3 to 5 days. Patient knowledge was assessed pre and post education programme, with significant results. Prior to the training intervention, 50% of subject knew brand name, doses and times, 55% knew the purpose of the medication and 15% knew of major side effects. On follow-up post discharge, results were 90%, 85% and 25%, respectively, easily demonstrating the effectiveness of nurse-led education programmes.

However, Furlong (1996) and Higgins & Regan (2004) questioned the effectiveness of education programmes, suggesting that to propose education alone significantly influences the effectiveness of SAM is too simplistic.

Further potential factors not highlighted in the Shen *et al*. (2006) study is that the intensity, length of time and one to one input or psychosocial support the educational programme provides from a healthcare practitioner may have had a positive impact on the patient's attitudes and behaviours towards medication adherence.

SAM and medication adherence

Self-management of medication can be referred to adherence to a medication regime and is of vital importance as part of any medication management initiative. The traditional terms compliance and concordance have negative connotations not reflecting a partnership approach, but medicines adherence is the newly coined terminology. National Institute of Clinical Excellence (2009) define adherence by type: intentional and unintentional, but this is a very simplistic view and does not take into consideration the multifarious nature of medicines taking behaviour. McGraw & Drennan (2004) claimed that adherence is the interchangeable relationship between three factors: patient-related factors, therapy-related factors and healthcare and system-related factors. Drawing from their review on the move from compliance to concordance in older adults, they give a detailed analysis of these three factors, including improved patient education, increased communication,

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improved labelling and packaging of medication, using prompts and reminders and simplifying medication regimes.

Debate exists as to whether SAM helps increase adherence. Ruppar et al. (2008, p. 137) reviewed four studies, which had researched adherence levels following SAM, and two of the four research studies identified reported 'significantly greater adherence outcomes' in the intervention group.

DiMatteo et al. 2000 suggested that the relationship between depression and adherence was such a significant one, with a suggested odds ratio of three to one that an individual diagnosed with depression was likely to not act upon health professionals recommendations that specific interventions were required to ensure adherence. Maidment et al. (2002) conducted a study specifically to capture adherence rates of antidepressant therapy in older people. Sixty-seven patients over the age of 65 with a diagnosis of depression receiving antidepressant therapy were interviewed using nine different assessment scales. Examples of these included the Mini Mental State Exam, Geriatric Mental State Schedule-Depression, beliefs about medicines questionnaire and the Global Adherence measure. Sixty-seven per cent were fully adherent, with factors such as information giving and carer support for medication administration enhancing regular taking of antidepressants. Although a small study which relied on self-reporting for adherence rates could introduce bias, this study does indicate that there is a significant issue with antidepressant adherence with older people, with almost a third of those interviewed non-adherent. The most significant result was 13.4% of patient never adhered to prescribed antidepressant therapy. Reasons identified for non-adherence in this study reflected the three forms of adherence outlines by McGraw & Drennan (2004), such as concern about the taking of antidepressants, severity of side effects, issues of dependence and long-term effects.

Patient perspectives on SAM programmes

Deeks & Byatt (2000) conducted a study reviewing patient satisfaction with SAM upon discharge from general medical wards. Conclusions revealed that 80.9% of patients would choose to self-administer in future, but only 18% of over 60s involved in the study were positive about the experience. In contrast to these results, Manias et al. (2004) conducted semi-structured interviews with cardiovascular patients that focused on their experiences of SAM within a hospital setting. One of the four key themes identified was the 'benefits of self-administration'. Manias et al. (2004, pp. 197 and 198) stated it was 'empowering',

was able to 'facilitate autonomy' and provided 'self-determination'. Although this study did involve older adults, as did Deeks & Byatt (2000), both studies did not provide specific focus on the older adult with mental illness and their perspectives of SAM.

Advantages and barriers of SAM programmes

Several advantages of SAM within the hospital setting have been highlighted, and Commission for Health Improvement (2009, p. 6) stated 'it can reduce problems associated with conventional medicines administration', with the NPC (2008, p. 6) adding it 'increases patient responsibility and autonomy' and ensures patients can make informed choices about their care. Self-administration of medication ensures that all treatment pathways are individualized to patients' needs, not to the routine dictated by the clinical area. Patients can customize their care (Collingsworth et al. 1997), adjust routines to fit their needs, simplify their medication regime to a system they can effectively use, and establish habits that can be integrated into their lives that will be continued post discharge. Swanlund et al. (2008) identified these areas as fundamental aspects of successful SAM schemes in their study of the implementation of SAM in older adults within the community setting. Self-administration of medication has the potential to increase self-confidence, provide security and reinstate confidence and control of their lives. Depression can cause increased dependence on those around them, so by providing the mechanisms and empowering people to increase independence, healthcare professionals can initiate a positive self-fulfilling prophesy for the individual.

In contrast however, reluctance from the patient was a surprising outcome from the study by Manias et al. (2004, p. 199), as it is perhaps wrongly assumed that with a patient-centred approach an individual would want to be empowered to self-manage their illness, but this research highlighted the perpetuating phenomenon of the 'sick role' (Faulkner & Aveyard 2002) and the subjects from the research stressed that they were 'ill', therefore 'required a nurse to administer their medication'.

From a professional development perspective, nurses have the opportunity to learn from the patient about how they manage their illness, which is resonant of the principles behind the Expert Patient Programme (Department of Health 2006). Although not specific to mental health, working in a collaborative way to share responsibility for the management of chronic illness, it is a beneficial way to boost patient self-belief and use of their skills and knowledge about themselves. This can prevent relapse, in turn focusing on recovery from illness. This approach was adopted by the Department of Health's Mental Health

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Task Force (2001) to challenge the traditional approaches to treating mental illness, with a shift towards individualized care, reaffirming control to the patient over their own lives, with a thorough review of its implementation being provided by Anthony (1993).

However, both medical and nursing staff's reluctance to take on board these principles and embrace the positive aspects of SAM has been highlighted as a potential barrier to its implementation. This is closely associated with issues of power and control between healthcare professionals and patients, and may be the influencing factor for the lack of realization of SAM by mental health services. Manias *et al.* (2004) argued this is a major barrier, but were confident that a well-researched, planned staged approach to implementation would overcome these issues. Also, by using key stakeholders from within the multidisciplinary team, change could be integrated, continuously reflected upon and successfully maintained.

Ethical and professional issues

The Nursing and Midwifery Council (NMC) provides guidance for Registered Nurses on the SAM in 'Standard 9, Standards for practice of administration of medication' (NMC, 2008, pp. 29 and 30). However, this advice generally lacks specificity or detail, minimally outlining assessment criteria, briefly mentioning patient capacity and introducing basic self-administration levels. However, the most significant aspect states 'Whilst the registrant has a duty of care towards all patients the registrant is not liable if a patient makes a mistake self-administering as long as the assessment was completed as per local policy . . .' (NMC, 2008, p. 30). There is a clear indication that although guidance is available from the NMC, local policy is paramount for SAM programmes to safeguard those Registered Nurses and patients involved in such schemes.

The SAM project within OPMH

Review of the literature highlighted minimal progress on the implementation of SAM within mental health services. Two papers within the field of psychiatry were identified: Coudreaut-Quinn *et al.* (1992) looking at adherence through SAM programmes, and Visalli *et al.* (1997) focusing on SAM being a consumer-driven initiative, but these papers were not contemporary, neither including older people with mental health problems, nor reviewing the potential implementation of SAM in OPMH inpatient environments. In order to answer the three questions posed at the start of the review, a multidisciplinary team comprising nursing, medical and pharmacy representation convened to discuss the possibility of a SAM project within OPMH

services. The NPC (2008) service improvement guide detailing how SAM could be implemented within Mental Health Trusts was consulted. This guide recommends using a PDSA cycle (NHS 2003) for implementing clinical practice improvements (Box 1).

Box 1

Description of the Plan, Do, Study, Act cycle (NHS 2003)

- Plan what you are going to do, after you have gathered some evidence of the nature and size of the problem.
- Do it, preferably on a small scale first.
- Study the results. Did the plan work?
- Act on the results. If the plan was successful, standardize on this new way of working. If it wasn't, try something else.

Although the Trust did have a self-administration policy, it lacked specific elements the team felt it required, so following a review of the research literature and SAM policies and procedures, a new SAM pathway was developed which provided OPMH specific assessment criteria. This reflected the NPC (2008) underpinning principles for SAM. Namely an environmental risk assessment and action plan was completed to ensure the policy was in place. This included full multidisciplinary team (MDT) support, environmental provision of secure lockers to facilitate the scheme, patient preparation and education strategies, ward medics and Registered Nurse responsibilities. Also addressed were the stages of SAM specific to our patients' needs, a means of reviewing patient competence with inclusion and exclusion criteria and a model for ongoing support following discharge.

The pathway included:
1. Assessment pro forma with specific inclusion/exclusion.
2. History taking including physical and mental health.
3. Risk assessment.
4. Functional assessment of physical abilities.
5. Determined levels specific to our patients' needs.
6. Patient consent form.
7. Patient information leaflet prior to commencing SAM.
8. Mechanisms for patient education and support throughout SAM.
9. Procedures for monitoring progress, adherence to SAM and feedback to MDT.

Whilst the protocol was being developed, members of the team collated pertinent information that would benefit the implementation of the project. The plan was to visit

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Table 1
Summary of Registered Nurse responses regarding self-administration of medication

Experience	Four out of five nurses had no experience of self-administration of medication. Previous experience was from Adult Mental Health where patients self administered from medication boxes under supervision from a Registered Nurse.
Understanding	Patients are supervised, monitored to take medication s they would at home. Administering medication under supervision of a Registered Nurse, either from a patient own drugs or similar patient compliance aid.
Benefits	Familiarizing patients with medication manage successfully at home; it highlights potential risks or difficulties for patients. Fully prepared before discharge. Increased confidence. Staff monitoring the ability to self-administer and compliance. Increased awareness of their medication. Maintain independence and skills ready for discharge. Promote recovery. Time saving, safer, less errors. One to one time spent with patients.
Difficulties	Increased pharmacy workload. Unwilling patients. Time consuming. Time constraints. We have to be careful as trained nurses to see the patients taking the medication and to sign. Frequent medication changes. Confusion at tablet recognition of different suppliers.
Obstacles	Pharmacy services and resources, carer-led administration. Time constraints. Clear policy and procedure needs to be *in situ*. Understood by nursing team, Patients with cognitive impairment or short-term memory deficits.
Risk	Ensure process fully supervised. Tablet identification. Storage of tablets. Where administered from.

areas within our Trust where SAM programmes were being implemented, such as Adult Mental Health Services. We aimed to explore the patients' perspective to determine their viewpoint, but we also needed to gain the Registered Nurses' perspective, investigating their professional learning and educational needs.

For the purpose of this project, patients' views on the potential implementation of self-medication were gathered using a simple questionnaire comprising open and closed questions. Of a small sample (35 people over 60 years, with functional mental illness on an inpatient ward) the view was generally positive, comments such as 'Because I do know how to take my medication' and 'When I go home, I need to do it myself' were made.

For the Registered Nurses on the ward ($n = 5$), a questionnaire was circulated to gain information related to their knowledge of self-administration programmes, potential benefits, perceived difficulties, obstacles, risks and their learning needs for implementation. See Table 1.

We are now at the 'Do' stage of the PDSA cycle (NHS 2003), but the project has encountered several areas that have impeded progress. On a positive note, the project was presented to a conference delegation, and was well received across many different areas of clinical care.

The SAM pathway was shared with key stakeholders within OPMH, actively seeking comments on the actual pathway itself and its implementation, and was again positively received, with it being presented at the OPMH Essential Standards meeting, where issues of governance are discussed and once more an optimistic reception was gained.

However, resource implications relating to pharmacy support staff were highlighted at this point as outlined by Wright *et al.* (2006). A lack of resources would mean that if patients were assessed to require a compliance aid such as dossett box or nomad, there would not be the pharmacy staff to provide this service. For the duration of the pilot

project the pharmacist stated that he would assist the ward staff in setting this system up for individual patients to overcome this potential barrier.

There are still areas left to address such as detailed discussions with the Trust Risk Manager to ensure that safeguarding measures for both staff and patients are addressed and sharing the pathway with the Clinical Patient Safety Committee will also be required.

There is also the need to put together a teaching and education package for all staff working within the clinical area in order to educate patients regarding their medication, but this will need to reflect the success implied from the study reported by Shen *et al.* (2006). Presently the Registered Nurses attend a Medicines Management Workshop and have annual medication administration assessments. As highlighted in their questionnaires, their needs will be immense, but to ensure they are confident and feel proficient in implementing the pathway, a full day workshop is planned to share the pathway, explore their concerns, solve the problems, and finalize the paperwork.

Conclusion

Within OPMH services there is a definite need to move from the traditional, paternalistic clinical care practices and provide forward thinking, innovative projects that are resonant of a individualized, person-centred approach to care. Self-administration of medication programmes are a method by which this can be achieved. Researches suggest that not only are patients more satisfied with their care, but it contributes to greater autonomy, decision-making and independence, empowering people to self-manage illness, in turn ensuring they are the expert in the journey related to their health. Successful projects have ensured that by understanding the processes by which people manage their illness, including medication taking

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attitudes and behaviours, adherence to healthcare regimes can improve. It is also a requirement that the issues related to self-management of medication are viewed from their perspective. There are risks associated with SAM programmes, but with positive risk management, these can be minimized.

However, despite all the positive researches focusing on patient-related outcomes and benefits of SAM, there is minimal innovative work being done within mental health services to implement this simple yet effective initiative. Unfortunately we are unable to answer the three questions posed at the commencement of this project, but it is imperative that this project continues to work through the PDSA cycle, ensuring that future work addresses any barriers to the successful implementation of SAM within OPMH.

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THE MENTAL CAPACITY ACT AND DEMENTIA RESEARCH

Aileen Murray provides practical advice on how researchers can use the legal framework to involve people with the disease in studies and give them a voice

Abstract

For research to have an impact on people with dementia, they need to be involved in studies. However, undertaking research with participants who may lack capacity to consent poses many challenges for researchers. This article explores the practical application of the Mental Capacity Act 2005 in the process and provides realistic advice on implementing its principles in research.

The Integrated Research Application System, NHS research ethics committees and NHS research and development departments can provide additional guidance. Knowledge of the practicalities of implementing aspects of the act that relate to research will ensure that researchers who wish to involve people with dementia can do so with ethical expertise.

Keywords

Dementia, ethics, inclusive research, informed consent, Mental Capacity Act 2005

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THE NATIONAL Dementia Strategy (NDS) (Department of Health (DH) 2009a) provided a framework to improve dementia services through increased awareness, earlier diagnosis and intervention, and high quality care. The NDS (DH 2009a) emphasised the need for evidence-based interventions for those with dementia through a co-ordinated research programme. However, Hellström *et al* (2007) argue that people with dementia continue to be one of the most excluded groups in society because of two factors: age and cognitive decline. Exclusion means that individuals with dementia rarely have their voices heard in terms of their treatment and care.

The rationale for this exclusion is complex. One possible explanation is that traditional ethical principles, when applied to dementia research, do not seem appropriate because they are limited in scope and flexibility. Hek and Moule (2006) outline four fundamental principles of ethical governance required to protect potential research participants: veracity, justice, beneficence and respect. They go on to stress the need for informed consent to be obtained in writing after full consultation with participants. However, this lack of flexibility potentially excludes people with dementia and the adequacy of these ethical guidelines is questionable (Loff and Black 2000).

Consent

When safeguarding people at risk such as those with dementia, health and social care practitioners' perceptions may hamper participation in research. Historically, consent to participate in research activity has been sought from a carer or relative of the person with dementia. 'Consent by proxy' or authorisation by another person, usually a family member or trusted individual (Cacchione 2011), to act on someone's behalf was acceptable in research involving those who did not have capacity to consent themselves.

This method was demonstrated by Werezak and Stewart (2002) who conducted semi-structured interviews with six individuals with Alzheimer's disease to explore adjustment to early-stage dementia. All participants lived at home with their spouses and written proxy consent was sought from spouses before participants' inclusion.

However, this research was conducted in Canada, where the Mental Capacity Act 2005 is not law, and it was undertaken before implementation of the act. During this study there was an assumption that the proxy's decision making was based on the wishes of the individual for whom they were consenting (Bravo *et al* 2003). The approach is outdated and not in line with a person-centred, inclusive methodology.

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> **Box 1** Mental Capacity Act 2005 two-stage test of capacity
>
> ■ Stage 1: does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?
> ■ Stage 2: does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?
>
> (Department for Constitutional Affairs 2007)

Beach *et al* (2005) argue that proxy decision making limits autonomy, but the ethical principle of respect for an individual is more complex than autonomy. It also includes interrelated concepts such as dignity and individuality of the person with dementia, central to which is the duty to protect patients who cannot make autonomous decisions. This premise is fundamentally linked to the need for best interest considerations under the Mental Capacity Act 2005 to include the person's past and present wishes and feelings, any beliefs or values that would be likely to influence the decision-making process if they had capacity, and any other factors they would have considered if able to do so.

Lastly, the assumed challenges involved in gaining favourable ethical opinion for research projects that involve individuals who lack capacity to consent often act as a barrier to researchers. The perception is that ethical approval will be declined on the basis of the nature of the illness. However, this perception is inaccurate and the guidance available in the Mental Capacity Act 2005 ensures that all aspects of any project are designed to include those with dementia in a safe, transparent framework.

Legislation

The Mental Capacity Act 2005 was introduced in England and Wales to ensure that those people who lacked the capacity to make decisions for themselves were given a statutory framework to support, guide and protect them. It also outlines who can make decisions, in what circumstances and how to do this. In Scotland the relevant legislation is the Adults with Incapacity (Scotland) Act 2000.

According to the act, where an individual's capacity to make a decision is to be determined, the two-stage test of capacity must be completed (Box 1). The capacity assessment should not be based on age, diagnosis or condition, appearance or behaviour (Department for Constitutional Affairs (DCA) 2007). The types of decision that are involved range from everyday, such as what to wear, to major decisions that may have a significant impact on their lives, such as future health, welfare and finance.

When determining capacity during stage 2, four points need to be taken into consideration:

1. Does the individual understand the information? Effort should be made to enable the individual to understand the information related to the decision. It may be presented verbally or in written form with specific focus on style, format and language used. Other forms of media may need to be used, such as pictures, video or music. If the individual and information giver have a good rapport or relationship, this may enhance understanding, similarly the reverse may have a negative impact. The time the individual has to consider the information may also be significant, in addition to how many times the information is presented to them. Family members or close friends may help the individual understand the information. Using a language the individual is familiar with may also help. Members of the multidisciplinary team may also aid understanding, for example, speech and language therapists. Their involvement would be essential in a person with neurological or cognitive impairment, enabling skilled assessment of the individual's abilities and development of communication interventions specific to their needs. Working in a person-centred manner to empower the individual is important to make stage 2 of the capacity test easier.

2. Retain information long enough to be able to make the decision If the individual is able to retain the information even for a short time, this must be taken into account. There must not be an assumption that they lack capacity. They may be able to retain the information but not communicate the decision, so communication will need to be made easier. The code of practice relating to the act (DCA 2007) recommends that enabling the individual to retain the information through prompts is beneficial, such as leaflets, notebooks, photographs or videos.

3. Weigh up the information available to make the decision To weigh up the information provided individuals must understand the pros and cons. These need to be provided in a format that will enable their understanding. Once more, time needs to be given to allow them to weigh up these points.

4. Communicate their decision Cheston *et al* (2000) state that 'dementia makes communication harder, but not impossible'. Effective communication is vital to ensure active engagement. A conversational rather than an interview tone should be maintained, ensuring that people are given time to support their train of thought. The use of visual prompts or cues to focus conversation should be considered, ensuring that attention is on spoken and non-verbal communication (Christie 2007). Many people can verbally state

their views. However, for those with complexities associated with neurological and cognitive impairments, additional support will be required. Written confirmation of their decision, sign language, drawings and observations using a picture board or Makaton® can be used. Simple hand gestures or muscle movements such as blinking an eye or squeezing a hand to confirm 'yes' or 'no' must also be considered.

Practitioners must not treat individuals with dementia as though they are unable to make a decision just because they make a decision that practitioners do not agree with. Dementia is an illness characterised by cognitive and neurological changes: loss of short and long-term memory, orientation, language skills, perception, judgement, understanding, social skills and personality changes are all possible. The individual has the right to make unwise decisions, and they would not be deemed to lack capacity on the basis that they have dementia. It is not a question of whether the individual can 'do' one or more of these four points, but more a process by which they are given the opportunity and supported with decision making.

Research activities

The act acknowledges the importance of research activities for those who lack capacity or with illnesses where capacity either fluctuates or is lost. Sections 30 to 34 of the act focus on research involving individuals who lack the capacity to consent to participate. The code of practice (DCA 2007) summarises what the act's rules for research cover:

- When research can be carried out.
- The ethical approval process.
- Respecting the wishes and feelings of people who lack capacity.
- Other safeguards to protect people who lack capacity.
- How to engage with people who lack capacity.
- How to engage with carers and other relevant people.

Although it is often used, the Mini Mental State Exam is an insufficient measure of whether those with dementia have capacity to consent (Howe 2012). Meulenbroek et al (2010) discuss the use of alternative tools that assess the 'competence' of an individual with dementia for research aims, such as the MacArthur Competency Assessment (Appelbaum and Grisso 2001). Meulenbroek et al's (2010) review concluded that the MacArthur Competency Assessment was beneficial in assessing capacity to consent, but using 'competence' as a measure of an individual's decision-making capacity does not take into account the nature of the decision being made.

The MacArthur Competency Assessment was developed before the act and does not take into consideration the specialised needs of those with dementia who may lack capacity to consent. Sherratt et al (2007) state 'capacity and consent need to be addressed simultaneously rather than as discrete processes' and developing a specific assessment tool for the research project to determine capacity to consent reflects the need for an inclusionary approach. The tool must be based on the two-stage capacity test (Box 1) to meet the requirements of the act. Further questions to include in assessment should take account of:

- Does the person understand that they can consent or refuse to participate in the research?
- Does the person understand what the research is about?
- Does the person understand and weigh up the benefits and risks of agreeing or refusing to take part?
- Has the person communicated their decision in any way?

If individuals have understood the research aims, are able to retain the information given about participation, can judge the risks and benefits of being included in the project, and can inform the researcher that they are willing to participate, they have the capacity to consent or not. If in agreement, they can sign the consent form.

If there are deficits identified in the assessment, the researcher may need to ask:

- How was the person's mental state at the time?
- Does his or her impairment fluctuate?
- Is there a better time of day to assess the person?
- Have they taken medication that will affect their cognitive status?
- Was the information presented in the clearest way?
- Can a family member or carer help make the assessment easier?

Researchers may need to revisit 'enabling understanding' and repeat their attempts with the potential participant. If all avenues of facilitation have been exhausted, a final decision will need to be made that the individual does not have the capacity to consent to participate in the research.

The researcher can check to see if a potential participant has an advance statement/directive that may be applicable to research activities. These are important documents for safeguarding and promoting a patient's interests, health and right to personal choices and decision making. According to the Mental Health Alliance (2005-2009): 'Section 4(6)(a) of the Mental Capacity Act explicitly states that when determining a person's best interests when that person lacks capacity, any written statement made when they

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Box 2 Integrated Research Application System (IRAS) questions and information about those who may lack capacity to consent

- What impairing condition(s) will the participants have?
- The researcher needs to justify the inclusion of adults who are unable to consent.
- An explanation of who will decide whether the participant has capacity to give consent, and what training or experience this person has for making such a decision.
- Does the research have the potential to benefit participants who are unable to consent for themselves?
- Will the research contribute to knowledge of the causes or the treatment or care of people with the same impairing condition?
- Risk or burden for the individual.
- What arrangements will be made to identify and consult persons able to advise on the presumed wishes and feelings of the potential participant?
- Is it possible that the capacity of potential participants could fluctuate during the research and how this will be handled?
- Criteria for withdrawal from the research.
- Considerations of advance decisions or statements by the participant.

(Source: NHS research ethics committee form, IRAS for which a user name and password are required)

had capacity should be considered.' If individuals have an advance statement, a copy can be requested from whoever holds it to make the consent process for their potential participation in the study easier.

If potential participants do not have the capacity to consent to participate in the research study, their involvement must meet one of two criteria:

- The research must have some benefit to the person who lacks capacity and aim to provide knowledge about the cause of or treatment or care of people with the same illness or condition.
- A consultee will need to be identified as per sections 30-34 of the act.

Personal and nominated consultees

The flexible, inclusionary approach to consent introduced by Gillies (2000) and Dewing (2002) ensures that the ethical principles outlined by Hek and Moule (2006) are adhered to, while recognising that it is only possible to gain a sense of what it is to have dementia from those with the illness. Hanson *et al* (2006) highlight the increased involvement of carers in service design, but stress that this ethos needs to be applied to research activities for those with dementia and their carers. Section 32 of the act states that 'reasonable steps' must be taken by researchers to identify individuals to be consulted before those who lack capacity are involved in research.

Personal consultee This is someone known to the prospective participant, such as a relative, carer or someone who has lasting power of attorney for personal welfare. The British Psychological Society (Dobson 2008) states that a personal consultee cannot be a paid carer or person who

has a professional relationship with the potential participant. Researchers are not seeking consent from the personal consultee; rather they are obtaining an opinion about the person's thoughts, feelings and wishes to participate. The researcher is trying to establish whether it is 'likely that the person would decline to take part, had they the capacity to decide' (Dobson 2008).

There is minimal information about carers being consulted, as recommended by the act. Lasseter *et al* (2011) used the act in their study and found that some consultees were surprised when they were approached for their opinion as they believed that their relative had capacity to make the decision. Others thought that the information letters sent out 'inferred greater levels of dementia in their relative than previously recognised'. This resulted in some difficult discussions with relatives. Substantial amendments were required to the supporting documentation for potential consultees (Lasseter *et al* 2011).

Nominated consultee If the prospective participant has no family or carer, or relatives do not think they can take on the responsibility associated with the decision, a nominated consultee may be sought. This is a person who is in a paid role or a professional who has a relationship with the individual, such as a solicitor, GP or independent mental capacity advocate (IMCA), but who is unconnected to the research. The role of the IMCA is to 'support and represent the person who lacks capacity and to audit the way decisions are being made'. The IMCA determines individuals' thoughts, feelings and wishes, asks questions on their behalf, and ensures their rights are upheld (DH 2009b). It is not the role of the nominated consultee to make a decision on behalf of the person, however. The decision is the responsibility of the decision maker.

Personal and nominated consultees must be willing to participate and provide the necessary information on behalf of the individual who lacks capacity. Consultees will be invited to participate and sign a declaration, which states that:

- The consultee understands the information given.
- They have been given the opportunity to discuss the research.
- They understand the person with dementia's involvement in the project.

Either role can be declined at any time. If the consultee declines to take on the role the prospective participant will not be disadvantaged in terms of care provided. If the consultee agrees to participate they can withdraw at any time from the research project or withdraw the individual who lacks capacity.

Ethical approval

According to the code of practice (DCA 2007), all research projects involving those who lack the capacity to consent must be approved by an 'appropriate body': 'In England the appropriate body must be a research committee recognised by the Secretary of State.' If researchers are studying for a course at university where research activities are undertaken and there is a requirement for ethical approval, the university ethics committee is not considered to provide sufficient scrutiny or independence, and is therefore not deemed an appropriate body.

Approval by the Social Care Research Ethics Committee (REC) or an NHS REC is required for research with participants who meet the requirements of the act. This will guarantee that an independent expert opinion is sought on whether the research protects the rights and wellbeing of the proposed participants.

The Integrated Research Application System (IRAS) (www.myresearchproject.org.uk) is designed to simplify the ethical approval application process. It is a single system for applying for approval for health and social care or community care research in the UK. The website is user friendly and it is easy to sign up for a user name and password. The first step is to complete the IRAS project filter form, which then chooses the appropriate forms that need to be completed. This in turn ensures that all the research ethical governance requirements are met.

The filter form asks 'Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?' By indicating 'Yes', depending on the type of study to be completed, it will highlight a section of questions specific to those without capacity to consent (Box 2).

The REC is concerned about the welfare of potential participants who lack capacity to consent, so researchers need to be clear about the possible risks and how these will be alleviated. Careful consideration has to be given to the potential physical, emotional or psychological harm that may result from inclusion in the research study.

If the researcher is unable to identify any risks, stating this to the REC via completion of the form will ensure that the researcher has given this due thought. Should the risk of harm emerge at any time during the research, however, the risk will be managed as appropriate through guidance and support from clinical and academic supervisors, and the project steering group. Answering all the questions required shows that all aspects of the act with regard to potential participants who lack capacity have been considered.

Box 3   Advice on involving those with dementia in the research process

- The ethics service makes a distinction between clinical audit and research. Research (seeking new knowledge) differs from clinical audit (evaluating the quality of something). Clinical audit does not need approval from a research ethics committee (REC), but it is deemed good practice to determine if individuals can consent and this also applies to clinical audit.
- It is advisable to allow for a minimum of three to six months for the application to ensure that this vital aspect of the research process is completed and submitted as per the REC's requirements.
- Obtain a copy of the Mental Capacity Act 2005 code of practice (Department for Constitutional Affairs 2007). This is an easy-to-use guide with information on proposed research activities involving those who lack capacity. The document is available online.
- If enrolled on a university course, contact lecturers who are familiar with the act to discuss and plan the application process.

- Speak to fellow students in the university who have been through the process – their insights are valuable. Use peers who have previously been through the Integrated Research Application System (IRAS) and are able to help.
- Contact lecturers who are familiar with the IRAS and have used it recently. The IRAS is continually upgraded so this is important.
- Choose academic and clinical supervisors who are aware of the issues of mental capacity in people with dementia.
- Attend study days for the IRAS if available. Attending a study day run by the company who built and maintain the IRAS site through a local university or research and development (R&D) department will be beneficial, or do the IRAS e-learning module.
- Contact the R&D department in an NHS trust for advice and support.
- Contact the Mental Health Act 1983 and Mental Capacity Act 2005 lead for the local NHS trust for advice.

- Ensure all the research paperwork reflects your understanding of the act.
- Develop a mental capacity assessment tool specific to your research project.
- Use your knowledge of working with those with dementia to design forms/paperwork that will be needed. Speak to a registered nurse, registered mental health nurse or any member of the multidisciplinary team working with people with dementia for advice and support.
- Speak to a speech and language therapist for advice on enabling understanding for those with dementia.
- As with all research projects and academic courses, peer support is invaluable, especially when going through a discouraging stage of the process. Whether the support is spontaneous, through a formal meeting or informal, peers can help motivate you to keep going (Murray 2011). Getting through the ethical approval process is a positive challenge with an immense amount of learning and support is essential.

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The forms that are designed for projects such as the mental capacity assessment, information letters and leaflets, consent for those with the impairing condition, and personal and nominated consultees need to be enclosed with the ethical approval application. The IRAS also provides online support.

Once the application is completed, a checklist is generated whereby all the requirements are checked before submission. However, before submission, the researcher must contact the Health Research Authority for a proposed date for ethical review. As the project includes participants who may lack capacity to consent to the research, a specific committee for ethical review will need to be attended. An REC reference number will be provided and this is then added to the application form.

The ethical review gives the committee members the opportunity to clarify any ambiguous aspects. This can help them to make the decision more quickly. However, if researchers are unable to attend, the committee will review the application in their absence. Written notification of the outcome of the review is sent within ten working days of the meeting. The committee may provide favourable ethical opinion, or a provisional opinion, and ask the researcher to clarify or change aspects. The response will be resubmitted for a chairperson's review. The committee will then confirm final ethical opinion within a maximum of 60 days from initial receipt of the application.

Finally, the researcher will receive a letter from the Health Research Authority confirming a favourable ethical opinion for the study to go ahead.

Box 3 (page 19) summarises practical aspects of the act and involving people with dementia in research.

Conclusion

People with dementia want to participate in studies (Howe 2012) and researchers have an obligation to ensure their rights and dignity are respected, maintained and protected. Hanson *et al* (2006) argue that older people should be more actively involved in research by contributing to methodological planning, data collection, analysis and dissemination. Surr (2006) states that by adapting research approaches, individuals with dementia can be empowered to participate in all levels of research activities.

One way of enhancing involvement is to adhere to the provisions of the act and its code of practice (DCA 2007). The act challenges the 'consent by proxy' approach, and has opened up the possibilities for people with dementia to be included in research and given a voice in a protected, transparent framework.

The act is explicit in its requirements for involving those who may not have capacity in research activities, and safeguards people with dementia through the use of consultees. The ethical approval process, starting with the IRAS and the ethical committee opinion, is a journey whereby all aspects of research governance for people who lack capacity are explored.

The act recognises the significant contribution of research with individuals with dementia to the development of preventative interventions, treatment and care. By following its guidance, the process will be less complicated and daunting.

Online archive

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Conflict of interest

None declared

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The effect of dementia on patients, informal carers and nurses

Aileen Murray explores the implications for three groups affected by the condition and how greater awareness of these results in improved experiences for individuals

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Abstract

This article explores the effect of dementia on individuals with dementia, their families and nursing staff. It explores the diagnostic issues that are important for individuals, the effect of symptoms and avenues of support. The need to adapt to different roles and the importance of communication are discussed for families and informal carers. Lastly, the culture of nursing care and the need for education, training, professional development and clinical supervision is discussed.

The literature emphasises the need for close collaborative working between those involved in dementia care, with individuals with dementia at the centre of decision making. It highlights how everyone involved can contribute to positive care experiences for those with the condition.

Keywords

Care provider, cognitive impairment, collaboration, dementia, family, mental health

IN 1906, German neuropathologist and psychiatrist Alois Alzheimer gave a lecture in which he described the case of Auguste Deter, a 51-year-old woman whose symptoms included memory loss, disorientation and hallucinations. Ms Deter died at the age of 55. At post-mortem cerebral atrophy was noted and neurofibrillary tangles and neuritic plaques were identified in her brain. The condition was later known as Alzheimer's disease, which is the most common cause of dementia (Alzheimer's Disease International (ADI) 2014).

Dementia is defined as (World Health Organization (WHO) 2010): 'A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.'

Incidence and prevalence

Worldwide, an estimated 36 million people live with dementia. This figure is expected to almost double every 20 years, to 66 million by 2030 and 115 million by 2050 (WHO 2012). Prevalence for men and women doubles for every five-year age band after the age of 65 (ADI 2008).

The Alzheimer's Society (2013) estimates that there are approximately 800,000 people in the UK who are living with some type of dementia. Prevalence rates by age are shown in Box 1.

Depending on the type of dementia diagnosed, symptoms may vary. Of the 100 or more illnesses and conditions that may cause dementia, most are rare. Of people with dementia, 62% have Alzheimer's disease and 17% have vascular dementia, while 10% have both (Alzheimer's Society 2013). Other dementias include dementia with Lewy bodies, Parkinson's dementia and fronto-temporal dementia.

Diagnosis

National Institute for Health and Care Excellence and Social Care Institute for Excellence (NICE/SCIE) (2006) guidance states that a diagnosis of dementia should be confirmed through a range

Box 1	Prevalence rates of dementia by age in the UK
■ 40-64 years: one in 1,400.	
■ 65-69 years: one in 100.	
■ 70-79 years: one in 25.	
■ 80+ years: one in six.	
(Alzheimer's Society 2013)	

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of procedures including cognitive tests such as Mini Mental State Examination and scans such as computed tomography (CT), magnetic resonance imaging, single-photon emission CT and molecular neuroimaging with positron emission tomography. These tests can rule out treatable conditions such as depression or vitamin B_{12} deficiencies, which can present with similar symptoms.

In their review of early onset – under the age of 65 years – illness, Svanberg *et al* (2011) identified that individuals, regardless of age, experience difficulties in diagnosis or long delays in receiving a confirmed diagnosis, which result in discrepancies in diagnosis rates (Alzheimer's Society 2013). Identified barriers to early diagnosis include poor awareness, lack of training in primary care and lack of specialist diagnostic centres or memory clinics.

Objective two of the National Dementia Strategy (Department of Health (DH) 2009a) is good quality early diagnosis and intervention for all, which involves 'rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis'. In addition, early diagnosis ensures people can plan for the future. Living with dementia as the disease progresses presents a significant challenge, as does living with the stigma associated with the illness. Non-disclosure is common, with the individual trying to conceal symptoms due to embarrassment. However, disclosure may feel like 'owning up' (Roach *et al* 2008) and sharing the diagnosis may be part of the coping process.

One interviewee told Harris and Durkin (2002): 'I tell everybody, you have no choice on this. You are in control of something [telling people] even if it is only that. What someone with this diagnosis can do is let people know.' This vignette shows that there can be hope, humour and growth (Aminzadeh *et al* 2007) after diagnosis. Initially, a diagnosis of dementia may be received with 'severe shock, with feelings of disbelief, anger, loss and grief' (SCIE 2013), but it can also provide a sense of relief after a difficult period of uncertainty.

Effect of dementia

Individuals In recent years, the subjective experience of dementia has been the focus of research reflecting a more person-centred approach, as families, friends and carers try to understand the experience of the person with the condition. Kitwood's (1997) work symbolised a significant shift in dementia care, challenging traditional perspectives while outlining the complexities of the illness. His work highlighted the need to ensure individuals were placed at the centre of their care, affirming their personhood and self-identity at all times.

Roach *et al* (2008) explored the experiences of younger people with the condition and identified three core themes: diagnosis, relating and restructuring. 'Relating' had a predominantly negative focus, inducing feelings such as guilt, helplessness and uncertainties related to the disease. Loss and grief were often experienced, with emphasis on 'loss of role, purpose, meaning, relationships, activities and identity'.

Coping with the illness, or 'restructuring', was a more positive adaptation phase. Harris and Durkin (2002) refer to 'role relinquishment and replacement', whereby roles are changed as a result of dementia and replaced with new positions and responsibilities. However, the distress that role change causes cannot be overlooked, such as the individual developing feelings of dependency or being treated like a child.

A sense of loss of control as symptoms become more pronounced has a major effect on individuals. Robinson *et al* (2012) identified a discrepancy between individuals' perceptions of their illness and symptoms and those of others. As a result, people with dementia may experience a loss of self-esteem and a changing sense of self. In addition, the traditional and prevailing perspective of dementia maintains that the illness is a threat to self-identity, characterised by multiple losses arising from cognitive decline, worsening orientation, reasoning and communication abilities. The result is a stream of distressing experiences for the 'sufferer' when misunderstanding or being misunderstood. These negative experiences are emphasised by narratives such as Sterin's (2002), who felt as if she was 'becoming invisible' as her condition worsened.

When describing her mother's illness, Grant (1998) stated 'the disease begins to turn its malign attention to the very heart of her self, as she struggles to hold her identity together', and Matthews (2006) further reflects this view, quoting carer experiences when trying to make sense of and cope with dementia and its associated symptoms: 'He's not the man I married' or 'She's not the mum I used to know'.

Roach *et al* (2008) and Nowell *et al* (2013) state that individuals with dementia need to reconstruct their self-identity to cope with and accept the experience. The ability to cope successfully requires an 'affirmation of past sense of self and identity' and there is a need for positivity and self-acceptance in the adaptation process. Individuals need to register, react

and adapt to the changes induced through dementia. If none of these occur successfully, interrelated coping mechanisms are not 'activated' (Clare 2003) and there is a threat to self-identity. As the illness progresses, the symptoms that are experienced may detract from the individual's identity.

This is a significant challenge because of the disease's poor prognosis, and living with the knowledge of the predicted deterioration in mental and physical health can be difficult to accept. Acknowledging that memory will decline and wanting to maintain a sense of self and identity (Harman and Clare 2006) make demands on individuals' abilities regarding self-preservation, and there will be an emotional response to this adaptation phase.

It is important to develop strategies to cope with perceived changes in loss of control, self-esteem and self-identity, for example, normalisation of everyday routines and structures. These strategies help individuals to gain control over the illness, and maintain independence, meaning and motivation. Adjusting to the illness and its challenges requires people to draw on what they know about themselves.

In a study examining the effect of being diagnosed with early Alzheimer's disease on identity construction, Beard (2004) highlighted three themes: defining moments, to tell or not to tell, and preservation. To preserve the identities they had before the disease, respondents used strategies to minimise 'exposure' of their difficulties, for example, they would avoid social events or tasks such as driving or cooking. Similarly, they evaded awkward questions or conversations to prevent difficult situations.

Beard *et al* (2009) explored how those with dementia cope by managing the condition as a disability, and incorporating this mindset into their existing identities. Respondents reported that using aids such as cognitive reminders, modifying their environments, assistance from others and acceptance of their symptoms by others, were important. Beard *et al* (2009) claimed that by reframing dementia into a disability, those with the illness felt more empowered about maintaining their identity.

Informal carers Those who look after family members, partners or friends who are in need of help because they are ill, frail or have a disability can be called informal carers.

Carers of those with dementia face multiple challenges and numerous losses. It is well established that caring for a relative with dementia can lead to financial difficulties, social isolation,

People take on caring roles because of love and affection, a sense of responsibility, guilt, or cultural expectations and social norms

physical and psychological problems (Schulz *et al* 1995, Lawrence *et al* 2008).

In most cases it is the spouse who takes on the carer role (Quinn *et al* 2010). If the individual with dementia is widowed or has no partner, it is often an adult child who takes responsibility. Evidence suggests there is a greater expectation on daughters to provide this care than sons (Ward-Griffin *et al* 2007). Other familial factors include geographical location, history or additional roles and responsibilities, such as having their own family. If there is no family then a close friend or neighbour may adopt the role of carer, but sometimes individuals face the illness on their own.

People take on caring roles because of love and affection, a sense of responsibility, guilt, or cultural expectations and social norms of filial responsibility. Caring for someone with dementia is almost always viewed in a negative light, although research by Svanberg *et al* (2011) with carers of individuals with early onset dementia found positive aspects including an increased feeling of gratification, altruism, personal wellbeing and a desire to reciprocate past support.

Walmsley and McCormack (2013) focused on the need to maintain high levels of communication between those with dementia and family members. Compromised communication poses a risk to both groups; individuals risk not being understood and making their needs known, often leading to frustration, anxiety and distress. Carers, by not understanding what is being said, risk inducing confrontation and may feel frustrated, helpless and hopeless. Walmsley and McCormack (2013) identified the need for meaningful reciprocal interaction because it improved the wellbeing of those with dementia and that of relatives. However, lack of understanding by carers and relatives about poor communication often contributes to carer burden or the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for older relatives (George and Gwyther 1986).

Informal carers are expected to manage an array of symptoms associated with dementia with no training and little support, such as wandering or impulsive behaviours, aggression, repeated questions and phrases, possible resistance to provision of care and also lack of recognition.

As a result the wellbeing of carers deteriorates and they can experience psychological difficulties such as caregiver stress in terms of sadness, loneliness and depression, and physical health problems. All of these have a negative effect on their ability to continue the caring role (Alzheimer's Association 2014).

There is evidence that informal carers experience a range of emotions such as guilt, anger, fear, helplessness, denial and depression (Markut and Crane 2005). Carer support groups, families, friends or counselling can help relieve the burden. Objective 7 of the National Dementia Strategy states that carers have a right to have their needs assessed (DH 2009a). However, a crisis in care may arise where caregiver burden exceeds resources. This crisis may be based on severity, accumulation or emergence of behaviour-related symptoms, caregiver exhaustion or caregiver illness (Vroomen *et al* 2013). If a crisis point is reached, older persons mental health services would recommend assessment at a specialist inpatient hospital. Avoiding institutionalisation is in the best interests of the person with dementia, but admission to hospital may be the only possible option to assess and treat any symptoms and determine a future care pathway (DH 2009a).

Formal care providers This is a person contractually employed in a health or social care setting, such as an acute psychiatric inpatient ward, care home or nursing home. Formal carers include support workers or registered nurses (RNs). They should receive dementia care training and have the appropriate skills, knowledge and continued education and support in the form of clinical supervision while working with patients or residents to ensure high standards of person-centred care. Nurses on acute psychiatric wards have high levels of occupational stress (Koivunen *et al* 2013).

Direct patient contact is one of the most satisfying aspects of mental health nursing (Wu *et al* 2010). However, the demands placed on RNs working on acute psychiatric wards – general shift management, paperwork, medication administration, ward rounds, care programme approach meetings, junior staff management and clinical supervision and liaison with other members of the multidisciplinary team such as social workers, occupational therapists or speech and language therapists – mean that this essential aspect of nursing care is diminished.

With reduced job satisfaction comes occupational burnout, causing work-related stress and sickness absence. In 2009, the Boorman review (DH 2009b) found that the direct cost of staff sickness absence was £1.7 billion a year, with NHS trust sickness absence rates ranging from 2% to more than 6%.

This in turn affects quality of care and safety of the ward environment because there is extra reliance on temporary and agency staff who might lack specialist training and skills.

In their review of nursing home staff attitudes towards residents with dementia, Brodaty *et al* (2003) identified that staff stress and burnout have a direct link to reduced resident wellbeing because there is less interaction between staff and residents. There are similarities between hospital and nursing home care as staff are still managing the symptoms that develop with the illness and the challenges that result for individuals and the staff treating and managing them.

In dementia care, continuity is important to ensure that patients feel safe and secure. If members of nursing staff are constantly changing it has a further negative effect on patient wellbeing.

The values and attitudes required by RNs to work with people with dementia are well documented (Norbergh *et al* 2006): compassion, sincerity, empathy, respect and empowerment. Nursing staff should work in partnership with those with dementia in an honest, open and therapeutic manner. These attitudes and values may be based on personal factors, knowledge, skills, training and experience of dementia care nursing, in addition to the organisational culture of the care environment.

Brooker (2007) discusses how care staff working with people with dementia should adopt the VIPS framework of person-centred care: values, individual approach, perspective of the service user and social environment. She stresses that person-centred care is only achievable if the larger organisation maintains an ethical code where those with dementia and nursing staff are valued.

If organisational culture is negative, this may influence nursing staff's attitudes. Norbergh *et al* (2006) state that this can 'result in their experiencing their own caring for the patient as meaningless and their work as worthless' and reduced job satisfaction. They imply that RNs' attitudes are of paramount importance when determining the quality of dementia care. Therefore, maintaining these core attitudes, values and ideals can improve standards of care and influence the guiding principles by which those with dementia are treated.

Nursing stress is encountered when these ideals are not achieved because of lack of resources or sufficiently skilled and educated staff to meet patients' complex behavioural, psychological and physical needs. However, there are numerous aspects that contribute to job satisfaction for nurses in acute psychiatric assessment wards that focus on dementia care (Zimmerman *et al* 2005). For example, when behavioural and psychological disturbances

are treated effectively and individuals are able to maintain a good quality of life.

When behavioural symptoms are treated, individuals with dementia will either be discharged home with community support, or if carer stress was high before admission, there has been a physical health decline or deterioration in cognitive status, successful discharge from hospital to a residential setting might be considered. High levels of job satisfaction among nursing staff in dementia care require on-going education, training, effective leadership and management of the clinical area with robust debriefing support mechanisms and clinical supervision to establish and maintain high quality care (Zimmerman et al 2005).

Conclusion

The complexities of dementia pose challenges for all. The profound influence of dementia on the lives of people experiencing the illness, their families and formal carers is well documented.

A collaborative partnership between all three groups is the most effective approach to improve care. Ensuring individuals have control over their illness is essential: education, treatment and care are vital to ensure that they are protected from malignant social psychology and disempowering processes. Education and training for carers focusing on positive interactions is needed. Formal carers require dementia knowledge and skills training to enable a person-centred culture to develop.

Training in understanding people's impairments and how these affect their behaviour and personality will result in symptoms being managed skilfully, with empathy and an understanding of the messages being communicated. Identity changes throughout the pathway of the illness are significant, and evidence-based support methods are still being explored. An increased awareness and recognition of the trifactorial effect of dementia can help to meet individual needs and ensure high quality care and services.

Online archive

For related information, visit our online archive and search using the keywords

Conflict of interest
None declared

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