University of Surrey

Faculty of Health and Medical Sciences

School of Health and Social Care

Student nurse perspectives on the impact of longitudinal home visits to people with dementia and their carers

*Whole Sight: New Ways of Seeing*

By

Wendy Jane Grosvenor

Research Project submitted in part fulfilment of the Requirements

Health Sciences PhD

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Declaration of Originality

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ABSTRACT/SUMMARY

**Background:** Multiple deficits have been identified in dementia education by UK policy makers and, from September 2015, the Department of Health mandated that undergraduate healthcare curricula included dementia. Here I explore one particular novel approach, the *Time for Dementia* Programme, which had at its core longitudinal learning from people with dementia and their carers.

**Objectives:** The study aimed to evaluate the impact of visits to the homes of people with dementia and their carers as part of the *Time for Dementia* Programme. To do this it explored adult nursing students’ perceptions of their professional learning and practice and career destination.

**Design:** This is a constructivist grounded theory qualitative study with data generated yearly over three years with the same 12 undergraduate adult nursing students. Data collection included: interviews (*n*=28), one focus group with 5 different participants in phase 2, reflective journals, and memoing. Literature was also recognised as a source of data.

**Ethical Considerations:** The study was reviewed and granted a favourable ethical opinion by the University Ethics Committee of the University of Surrey, UK.

**Findings:** What emerged from the data was the theory of *Whole Sight*, which resulted from participants’ *New Ways of Seeing* dementia. Findings suggested that as a result of their visits, participants reframed their perceptions of dementia, as attention was given to broadening their view of dementia, to encompass the person’s lives and relationships. Participants shared many examples of action, demonstrating the impact on their practice, as they questioned and changed their own approaches to care. Findings also highlighted that experiences of visits may have made participants more likely to consider working in the community.

**Conclusion and Recommendations:** Results indicate that visits created a positive dementia discourse that led to changes in practice. It offers new insights in developing dementia education that focuses on interconnectedness and caring relationships, promoting a *Whole Sight* focus on the person rather than on their dementia. Although experiences of visits may have made participants more likely to consider working in the community in the future, further research would be needed to explore this.

Findings suggest that participants realised that they can be active in their contribution to care, make change, and serve as change agents in dementia care; this may well also be relevant to other health professions.
Acknowledgments
Participants' willingness to share their experiences and perceptions of their visits to people with dementia and their carers through their interviews and reflective journals, enabled me to explore the impact on their learning through listening to their experiences of their visits. Without people with dementia and their carers' willingness to share their experiences, visits could not have taken place.

I would like to thank my supervisors Professor Ann Gallagher and Professor Sube Banerjee for their guidance and support in enabling me to reach my potential in my doctorate, they were inspirational.

I would also like to acknowledge my friends at Surrey University, who were always interested in my work and provided much needed coffee and humour throughout. Special thanks to Dr Allison Wiseman who was influential in motivating me to just get on with it.

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How you relate to us has a big impact on the course of the disease. You can restore our personhood, and give us a sense of being needed and valued. There is a Zulu saying that is very true, ‘A person is a person through others’.

Christine Bryden (2005:127)
Chapter 1: Introduction

Impact of longitudinal visits to the homes of people with dementia and their carers: Adult student nurse perspectives. ¹

The purpose of this Chapter is to provide an introduction to and rationale for the research topic. This PhD focuses on the perceptions of adult field nursing students’ listening to older people with dementia and their carers and exploring if, and how, this contact impacts on their thinking and practice. Consistent with a constructivist research approach, this Chapter also includes a discussion on reflexivity; exploring my own positioning within the research process. This research is set against a background of changes to healthcare professional training in dementia, with the introduction of mandated dementia education in healthcare professional training. My occupational background as a dementia specialist nurse, dementia teaching fellow and currently lecturer in older adult care in a University, accounts for my interest in an educational initiative evaluating the impact of visiting people with dementia and their carers on adult nursing students.

1.1 Overview of Chapters

This thesis is organised into six Chapters.

The introductory Chapter offers a description of the context of the study. The aim of this Chapter is to offer the reader an introduction to the research topic.

Chapter 2: Initial Literature Review explores the context of people with dementia in society, healthcare and education as well as the theories of dementia. This Chapter also considers the role of literature in constructivist grounded theory. A broad literature review of the involvement of service users with dementia in undergraduate adult nurse education is presented. This defined the existing parameters and provided a frame for the research by identifying existing knowledge and a rationale for the research. Different approaches to understanding dementia: personhood, social disability and citizenship models are explored, as each offer contributions that can reflect how to understand and respond to people with dementia. Perceptions of adult

¹ All student nurses choose from one of four fields of nursing to specialise in as part of their nursing degree – adult, mental health, child or learning disability. Adult student nurses work with patients over the age of 18 years.
nursing students working with older people and dementia as well as potential impact on career destination is also discussed.

**Chapter 3: Methodology** explores the choice of constructivist grounded theory methodology and methods are described and critically justified. Data collection methods and the process of data analysis are presented. The aims and objectives of the longitudinal nature of the research study are explored. Ethical issues related to this study and the measures taken to try to reduce the risk of harm to participants as well as the researcher are outlined. The measures used to assure credibility and trustworthiness of the study are also explained.

**Chapter 4: Findings and Discussion of Theory of Whole Sight** presents the findings that emerged from analysis of the data and addresses how the aims and objectives of the study were met. The first section of this Chapter presents the findings from the analysis of the reflective journals of participants’ visits. The next section explores the process of how the new theory of Whole Sight was identified, followed by the emergence of the core category of New Ways of Seeing and its related sub-categories of: Adaptive Thinking, Building Relationships and Transformative Learning. Extracts of interviews and the focus group are used throughout the discussion to clarify the process of the emergence of the theory, core category and related sub-categories to demonstrate that the theory and its related categories are grounded in the data. The final section of the Chapter provides an overall summary and discussion of the theory of Whole Sight, with existing literature integrated throughout to strengthen rigor.

**Chapter 5: Findings of Career Destination** addresses how objective 4, evaluating the impact of visiting people with dementia and their carers on adult nursing students’ career choices, was met. Discussion is integrated with existing literature, which is also seen as data in grounded theory.

**Chapter 6**: This final Chapter concludes the thesis, recommendations for nurse education and nursing practice are considered. The recommendations follow a critique and evaluation of the research and are compared to existing research to try and strengthen results of the study. Suggestions are also given for further research deriving from the findings of this study.

### 1.2 Background to the Study

Dementia is a global issue affecting 46.8 million people worldwide, this figure is predicted to increase due to ageing populations to 131.5 million by 2050 (Alzheimer’s Disease International 2010; Prince et al. 2015). The World Health Organisation (WHO 2017) estimate that there are
9.9 million new cases worldwide each year. Approximately 850,000 people are living with dementia in the United Kingdom (UK), by 2025 this figure is predicted to rise to 1 million (Prince et al. 2014). It is forecast that 27 per cent of males and 37 per cent of females born in 2015 will develop dementia (Lewis 2015). In the United Kingdom (UK) it is estimated that, at £26 billion a year, dementia costs more than heart disease, cancer or stroke (Alzheimer’s Society 2014a). Consequently dementia can be viewed as one of our biggest health and social challenges.

Although dementia is not restricted to people over the age of 65, it is estimated that the incidence doubles every 5 years from the age of 65 to 90 (Prince et al. 2014). Caring for people with dementia is a growing concern for ageing societies due to reported inadequate care provision, including people receiving poor quality care and support that does not meet their needs and aspirations (Alzheimer’s Society 2012:4). Watts and Davies (2014) suggest that there are a variety of factors which may contribute to poor dementia care by healthcare professionals. These include negative perceptions of dementia, along with a lack of investment in healthcare professionals’ education (DH 2010c). This research is set against the background of changes to dementia education, UK policy makers have made it clear that dementia education needs to be improved (Department of Health (DH) 2009; DH 2013; DH 2015; Prince et al. 2016). People with dementia are frequent users of healthcare services, consequently there is a need for quality dementia education to ensure the future nursing workforce have the knowledge and skills to support people with dementia.

The National Dementia Strategy for England (DH 2009), identified deficiencies in dementia skills and knowledge by healthcare professionals. Subsequent analysis of education and training by the Department of Health and Skills for Care (2010c), highlighted that the most significant gap to address was the lack of dementia education at the early stages of student nurse training. This view is supported by research, which reports that health and social care professionals, once qualified, do not feel adequately prepared to care for patients’ with dementia (Royal College of Psychiatrists 2011; 2013, 2017; Griffiths et al. 2014). The Prime Minister’s Challenge on Dementia (DH 2016) acknowledges the crucial role of education in: promoting high quality compassionate and culturally competent care to be delivered in dementia care. Nursing pre-registration programmes are the initial socialisation of students into professional nursing practice, providing interaction between theory and practice. Arguably they set the standards for the future quality of NHS healthcare provision by determining the knowledge, attitudes and competencies that are required. To try and achieve this, Benner et al. (2010) and Koren (2010), suggest that a more humanistic approach is required in nurse
education, one that incorporates both intellectual and emotional aspects of learning, focussing on the person rather than the disease process.

In a strategic approach to improve the quality of dementia care Living Well with Dementia – A National Dementia Strategy (DH 2009b) was launched which included on its cover, Putting People First. The strategy aimed to enable people with dementia to live well and involve them in decisions about their care, focusing on the concept of therapeutic potential throughout the dementia journey. Linked to a service commissioning framework, the strategy set out 17 key objectives in a bid to try and address deficiencies in dementia skills and knowledge. A key objective included ensuring an informed and effective workforce that were more mindful about the needs, as well as the experiences, of people living with dementia. This focus arose from policies such as; Forget Me Not (Audit Commission 2000) and the National Service Framework for Older People (DH 2001a). Furthermore the Kings’ Fund; Seeing the Person in the Patient, reiterated the need for dementia care to be personalised (Goodrich and Cornwall 2008). The Prime Minister’s Challenge further emphasised this vision; pledging that people with dementia and their carer’s are at the heart of everything, calling for action in research and education to improve quality of dementia care (DH 2015:2). This policy shift led to regulatory requirements to involve service users and carers in health education (DH 1999; 2000; 2001; 2003; 2005; 2008a; 2008b; 2010b). However the concept of patients no longer being passive recipients of care, is probably best captured by the DH vision of the NHS document titled; Liberating the NHS: No decision about me, without me (DH 2010a). This policy acknowledged a need for shared decision making, reinforcing the need to include the voice of people with dementia in health and education.

Service user and carer involvement has been a regulatory training requirement for some time for mental health and social work professionals (DH 2005; General Social Care Council 2005). However, nurse education only required the involvement of service users following guidance on involving them in the design and delivery of education following the Department of Health Education Commissioning for Quality report (DH 2009a). Supported by the Willis Commission (2012:6) review of nurse education which proposed that; person centred care should be the golden thread that runs through all pre-registration education. Willis’s (2015) more recent review of nurse education reinforced that the best healthcare is focused on the specific needs of patients and their carers/families. Therefore it is vital that healthcare education responds to care delivery that is evolving in order to ensure future health care professionals are equipped to support future health care needs. To achieve this vision of health and education for nurses,
Willis (2015) advocates that, nurse education and curricula development requires greater flexibility and innovation to focus on the needs of patients. It could be argued that the absence of cure in dementia further increases the emphasis on quality of life as the overarching principle of dementia care. The need to understand the subjective experiences of people living with dementia has become an increasingly dominant theme in the literature around personhood. Everybody is different, consequently the impact of dementia needs be viewed within the context of each person’s life (Lillyman and Bennet 2012; Towle et al. 2010). Diekelman (2003) asserts that reflecting on the lived experiences of service users is an effective learning perspectives to understand human responses to health and illness. One of the great powers of personal narrative, in my experience, is that it invites us to try to walk in other people’s shoes for a while; whilst reflecting on our own situation. Kleinmann’s early text, *The Illness Narratives* (1998), utilised stories to try and help health care providers to identify the psychosocial context of illness and focus on the perspectives of patients. The value of using patient stories in healthcare education is increasingly being recognised and explored to help challenge assumptions; create an emotional resonance; enhance learning (Haigh and Hardy 2010; Nizette et al. 2012) and facilitate a person centred approach (Levitt-Jones and Bourgeois 2011).

As Moon (2008) suggests:

> .... story can capture the holistic and lived experience of the subject being taught, it can tap into imagination, emotions and form new and meaningful connections between existing areas of knowledge. (Moon 2008:232)

Willis’s review of nurse education further emphasised that:

> Nursing education should foster … a caring professionalism that … respects the dignity and values of service users and carers (Willis 2012:6).

Interpretive pedagogies such as narratives; or stories, are often used in nursing as an approach to help students develop an increased understanding of a person’s experiences of chronic health conditions (Ironside 2006; Kear 2012). According to Ironside (2006), narrative pedagogies can provide learners with different perspectives with which to interpret the nature of knowledge. This view is supported by Moon (2004), who also proposes that stories can be a vehicle to help facilitate learning instead of imparting knowledge. Sharing uniquely human experiences can often enable people to connect with others (McDrury and Alterio 2003). This has led some practitioners to suggest that enabling patients to share their unique experiences may help to encourage the development of practice that is sensitive, individualised and empathetic (Costello and Horne 2001; Repper and Breeze 2004). Furthermore Moon (2010),
implies that listening to stories can help to build new knowledge on existing knowledge to bring about a change in understanding. Phelps (2004), suggests that emotional reactions to experiences may help contribute to the development of new attitudes and habits, which Charon (2007) proposes can be used to build human connections to create authenticity in relationships between practitioner and patient. Bailie et al. (2012b), explored student nurses’ experiences of caring for people with dementia in hospital. They found that nursing students reported that acquiring life stories of people with dementia from their carers helped them to understand the person better as an individual. Hence to ensure holistic understanding of the needs of people with dementia, educators need to ensure that their experiences and thoughts are given equal importance to the biomedical knowledge of the disease in the curricula. Accessing these personal experiences are essential as they can offer nursing students’ an insight into the subjective experiences of dementia.

1.3 Evolution of Service User Involvement in Educational Context

Service user and carer involvement in the design and delivery of nurse education was mandated, in the UK, by both the Department of Health Education Commissioning for Quality document (2009a) and the Nursing and Midwifery Council (NMC 2010 Requirements R5.1.2). More recently the Willis Commission (2012) report on the future of nursing education, recommended that the experiences of patients should be at the heart of nursing education to help improve practice. Despite the mandate, the extent to which involvement in nurse education has been translated into active partnerships rather than tokenistic consultation (Forrest et al. 2000:54) has been debated. However, lack of a clear definition regarding what service involvement actually encompasses could be a contributory factor to lack of engagement with service users (Morgan and Jones 2009; Spencer et al. 2011; Rhodes 2012).

The National Co-ordinating Centre for Public Engagement (NCCPE) (2009) describes public engagement as generating:

…mutual benefit – with all parties learning from each other through sharing knowledge, expertise and skills. Done well, it builds trust, understanding and collaboration, and increases the institutions relevance to, and impact on civil society

(Spencer et al. 2011:8)

This viewpoint succinctly reflects my motivation and engagement to explore an innovative educational initiative that moves beyond the rhetoric of involvement, to more meaningful engagement of people with dementia and carers in undergraduate adult nurse education. It
also reflects the shift in health and social policy from pathology to people (Reid et al. (2001:377). Terry (2012), suggests that working in partnership places a value on the expertise of service users (experts by experience) as well as carers, and is recognised as integral to student learning (Gutteridge and Dobbins 2010). Both Spouse (2001) and Towle et al. (2010), suggest that students can be more present and respond to patients’ individual needs through social interaction, enabling them to see beyond patients as stereotypes. Haigh and Hardy (2010) posit that emphasising the human dimensions of nursing care may benefit clinical practice.

An important reason to involve people with dementia and their carers in education is to try and attempt to redress the marginalisation that they often face as a result of their dementia. Service user involvement is seen as a way of ensuring that research is relevant to the groups that it intends to inform and give a voice to the knowledge that is, according to Cotterell and Morris (2012), seldom heard. Patients are gaining a more active role in health care with a move towards partnership which is reflected in the phrase ‘Nothing about me without me’ Cummings and Bennett (2012). This phrase reinforces the ethical argument that people have a right to be involved in health care or research interventions. Wilson et al. (2015) suggests that as citizens, there is a clear moral argument for service user involvement to ensure that they have a voice in public services they are paying through taxes and labour, arguing that this is particularly relevant to health and social care services and publicly funded health research. Consequently the voice of people with dementia should form a core part of undergraduate adult nurse curricula, otherwise there is a risk that their voice is ignored and they remain marginalised. The involvement of people with dementia and their carers is an attempt to try and redress the marginalisation and conventional assumptions of dementia.

1.4 Dementia Education in Higher Education Institutions

The education of our nursing and care workforce over the next ten years will determine the strength of our healthcare system for decades (Willis 2015).

Although nurses make up the largest group of healthcare professionals in the UK (Willis 2015); Snow (2012) identified that between 2008 and 2013, there was a loss of approximately 4500 places as a result of a decline in commissioned training places for nursing, which resulted in a 17 per cent reduction. This reduction prompted the Royal College of Nursing (2012) to express concerns about the impact of commissioning on the supply of nurses to the UK. In an attempt to address the workforce deficits, especially in aged care settings, nurses have been recruited from overseas. However, as Blake (2010) argues, this cannot and should not be seen as a
long term solution to recruitment. Furthermore recent changes to funding, replacing the bursary scheme in favour of student loans for trainee nurses and other health care students have led to increasing concerns about student nursing numbers, consequently exacerbating existing workforce deficits (The Kings Fund 2017). Following these changes, The Kings Fund (2017), investigated the number of applications for undergraduate nursing places in the UK in 2017, and identified that numbers had decreased 19 per cent from 2016. However the full impact of changes to funding will take time to emerge.

There have been consistent calls for all healthcare staff to be educated appropriately for their role (Royal College of Psychiatrists 2011; Banerjee et al. 2016; Boaden 2016), with critics arguing that education has been slow to respond to ensure that the future healthcare workforce is prepared to provide the skills needed to support people with dementia (Pulsford, Hope and Thompson 2007; Tsolaki et al. 2010; St Clair Tullo and Gordon 2013; Alushi, Hammond and Wood 2015). People with dementia are significant users of healthcare services, consequently dementia education needs to ensure that the future nursing workforce is skilled in providing high quality care to people with dementia (Collier et al. 2015; Prince et al. 2016). Deficiencies in both the knowledge and skills of healthcare professionals caring for people with dementia were highlighted in the National Dementia Strategy for England (DH 2009a). To address this gap, the Department of Health published: Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values (DH 2013), mandating that by September 2015 undergraduate healthcare curricula included dementia (DH 2013; Daley and Grosvenor 2016). Nursing pre-registration programmes are the initial socialisation into professional practice, providing interaction between theory and practice, setting the standards for the future quality of NHS healthcare provision in dementia care.

Prince et al. (2016:66) argue that whilst in service dementia training is important, they suggest that a greater commitment towards dementia care in the education curriculum would deliver greater and more sustainable benefits for people with dementia, and ensure a workforce fit for purpose. Although dementia education is mandated by Health Education England (HEE), the Nursing and Midwifery Council (NMC), (the professional regulatory bodies (PRB) for nurses, it does not explicitly include dementia in their requirements for pre-registration education providers. Universities’ health curricula are based on the PRB’s requirements and although the Nursing and Midwifery Council's (2010) Standards for Pre-registration Nurse education included a competence for working with people with cognitive impairment, for students in the adult, mental health and learning disability fields, it did not explicitly include dementia. Critics argue that this may lead to variation in the extent to which dementia is included, leading to
variation in dementia knowledge, attitudes, skills and competencies of those completing pre-registration programmes (Knifton et al. 2014; Willis 2015; Banerjee et al. 2016). Significantly an NMC review of new standards of proficiency for future graduate registered nurses was published during this PhD research in 2018, and will be adopted nationally from September 2019 (NMC 2016). Although person centred care is referred to throughout the new standards, the importance of the person as a unique individual, their perspective, relationships with others and the role of families is not recognised. Although the new NMC standards for pre-registration nursing programmes, Realising professionalism: Standards for education and training, proposed by the NMC (2016) explicitly mentions dementia, unfortunately it does not explicitly identify the need for nurses to recognise the human value of the person with dementia.

Although there is increasing interest in improving dementia education, evidence suggests that provision of dementia education in undergraduate adult nurse curricula is limited, whilst little is known about the quality of its content (Baillie et al. 2015). This concern is reflected in a number of UK reviews of medical and other undergraduate health and social care programmes (Pulsford et al. 2007; StClair Tullo and Gordon 2013; Alushi, Hammond and Wood 2015). Pulsford et al. (2007), in a scoping review of social work, adult and learning disability nursing programmes revealed UK Health Education Institutes (HEIs) (n=22), provided a mean of just 3 hours dementia related teaching during the 3 year undergraduate adult nurse curricula. A more recent analysis by Alushi, Hammond and Wood (2015) identified that little had changed, they found that dementia education only averaged 2 to 3 hours throughout the entire 3 year undergraduate nursing curriculum. It could be argued that the impact of this is reflected in numerous research studies which identify that health and social care professionals do not feel prepared to cope with people with dementia (Royal College of Psychiatrists 2011; Young et al. 2011; Watts and Davies 2014; Baillie et al. 2015). HEIs could be accused, however unintentionally, of promoting stigma and poor quality dementia care by failing to adequately include the care of people with dementia in their undergraduate nursing programmes. Despite the fact that the new NMC standards aims to provide HEIs with more flexibility for creativity and innovation in delivery of nursing programmes, the standards do not fully address current inconsistencies in the delivery and content of dementia within individual curricula. Consequently many researchers express concerns that mandated dementia education may result in a tick box exercise, with little meaning or value attached resulting in no real impact on student’s skills, attitudes or competencies to effectively caring for people with dementia (Traynor et al. 2011; Knifton et al. 2014; Collier et al. 2015:732; Surr et al. 2017).
Critics argue that as a result of undergraduate nursing curricula’s focus on teaching technical skills, nursing students’ frequently associate contemporary nursing with acute care technology (Algoso et al. 2013, Duggan et al. 2013). The practice of nursing is more than a completion of tasks, as Benner et al. (2010) suggests, it also involves good communication skills and the ability to manage care from the perspectives of the patient. Benner et al. (2010), criticise current nurse education for routinely utilising outcome based, conventional pedagogies that use didactic educational strategies, focusing on teaching rather than learning. Brown et al. (2009), in a descriptive study measuring the use of a variety of pedagogical styles worldwide, identified that 56 per cent (n=946) of nurse educators used conventional teacher-centred pedagogies that focused on meeting behavioural outcomes and covering content. Arguably this dependence on conventional pedagogies is a result of a content saturated nursing curriculum (Diekelman and Smythe 2004; Giddens and Brady 2007). Nurse Educators argue that this didactic approach has the propensity to create passive learning (Benner et al. 2010; Dewing 2010; Fink 2014). Belleck (2008:440) reinforces this criticism, suggesting that this teaching centred approach makes nursing curricula, teaching heavy and learning light. This view is supported by Treacy (1987) in Ferguson and Jinks (1994:689), who described teacher centred methods such as lectures as teaching that fails to touch the students’ reality.

Dalley, Candela and Benzel-Lindley (2008) warn that in response to new knowledge, nurse educators often add to curricula, arguing that existing content is rarely reviewed or removed, resulting in overcrowding of the curricula. Blumberg (2009), criticises these approaches, arguing that they can fail to engage the student or address their application of prior learning and preconceptions. Evans (2004:9) aptly describes this as a painting by numbers culture that is inherent in many HEIs. If nurse educators are to encourage nursing students to learn about the whole person and not just the disease process, nurse education needs to evolve in order to reflect this (Ironside et al. 2003). Bevis and Watson (2000) suggests that if nurse education is to move towards a caring curricula it has to be based on the needs of the learner and community, moving away from the rigid behaviourist Tylerian model of objectives driven curriculum development. Originally developed by Tyler (1949), to satisfy the requirements of performance-based model of health professionals’ education. Nurse education must evolve to be more forward thinking, adopting innovative learning strategies such as stories, if it is to adequately prepare adult nursing students to care for people with dementia and their carers. Educational initiatives involving service users is an approach that may enable nursing students to better understand the experiences of people with dementia.
Mandated dementia content in nursing curricula presents HEIs with unique challenges as well as opportunities, to help prepare future nurses to address the complexities of working with people with dementia in a variety of settings (NMC 2010; Baillie et al. 2015). Willis (2015), in his review of nurse education, criticised undergraduate nurse education for remaining fixated on the hospital model of care whilst not addressing shifts towards community care. The driver for this is the shift away from care in hospital to service users' homes (DH 2000). Supporting people with dementia to stay in their homes is viewed by many as key to helping the person to maintain a sense of self and identity (Kitwood 1997; Milligan 2009; DH 2000). Milligan (2003) suggests that the presence of familiar objects and familiar visual cues may help to support people with dementia to maintain their identity and sense of self, Auge (1995) refers to this as anthropological space. An estimated two thirds of people with dementia live in their own homes with the support of carers and/or other support networks (National Audit Office 2010; Alzheimer’s Society 2016). If this number is correct, it would indicate that there are approximately 570,000 people living at home with dementia, however it is claimed that more research is needed in this area to ensure these statistics are more reliable (UK Homecare Association 2015). There is a clear need for nursing curricula to reflect the changing landscape of the workplace and innovate to enable nursing students to understand the contexts of the lives of people with dementia. It is essential therefore, to design a proactive dementia nursing curricula, rather than one that is reactive to ensure that it directs and informs the future nursing profession.

The World Alzheimer Report (2016) advocates for the development of experiential methods of teaching that involve experiences of patients; arguing that they engage staff at an emotional level (Prince et al. 2016). Despite the increasing involvement of service users in the education of healthcare professionals, little attention seems to have been paid to how experiential methods of teaching are incorporated, or evaluated, into a nursing curricula that is often based on the scientific paradigm (Towle and Godolphin 2013). Higher Education Institutions (HEIs) have a role in ensuring dementia education is meaningfully embedded in undergraduate nurse education; arguably this is the greatest challenge faced by educators. Collier, Knifton and Surr (2015:732), suggest that despite the mandate to include dementia in the curricula, many HEIs may find that the pressure to do it, will take precedence over doing it well. As previously highlighted undergraduate nursing curricula continues to be increasingly overcrowded as more content is added, often without review or removal of existing content and this reflects the experience of the researcher. In order that dementia education is effective, educators need to engage students to try to understand its value and its contextualisation to their current and
future practice. Crookes, Crookes and Walsh (2013:239) share this view, arguing that
undergraduate students are often unwilling to engage with topics if they cannot envisage their
application to practice. The root of the word educate means to draw out, not to fill the student
with facts (Palmer 1996:43); and as nurse educators it is essential that undergraduate
dementia education is facilitated in a meaningful way that engages with people with dementia
and links theory and practice. Freire (1993:81) characterises the act of teaching as the practice
of freedom. As Moon and Fowler (2008) propose, listening to stories can often provide a holistic
understanding of a persons’ lived experiences which can encourage active learning by nursing
students rather than merely transition of knowledge. Mann and Himlein’s (2008) quantitative
study involving psychology students, identified that the use of a first-person narrative teaching
approach reduced mental illness stigma, when compared to a traditional diagnosis-centred
teaching approach. Furthermore Bate, Robert and Maher (2007:69) suggest that:

In a field of practice criticised for the many ways it can dehumanise and detach,
storytelling in healthcare helps to personalise and connect.

Tee (2012) supports the authentic engagement with service users in education, arguing that it
may help to address the crisis in confidence in healthcare.

1.5 Positioning of Study

This PhD study is linked to a larger programme of work, the Time for Dementia Programme
(http://www.sussexpartnership.nhs.uk/whats-new/time-dementia-2). This thesis explores the
experiences and perceptions of Bachelor of Science nursing adult field students (n=12), of their
visits with people with dementia and their carers over three years as part of a wider Time for
Dementia programme (Banerjee 2016). Visits were integrated into undergraduate students’
practice learning placement hours. Comprising 50 per cent of curriculum hours in the UK,
practice learning placements are an integral part of nurse education and have been identified
as an important influencing factor on nursing students which will be explored later in the thesis
(subsection 2.17) The aim of the visits was to introduce the perspectives of the person with
dementia and their carer into healthcare professional students’ understanding of dementia.
Integrating the voice of the patient in education is in line with the Shape of Caring review of
education by Willis (2015), who advocates enhancing co-production of education with patients
as one of his main themes. People with dementia and their carers informed the wider
programme of work as they were involved in the design of the programme from its conception
and continue to be involved with its development as advisors on the Time for Dementia steering
group which meets quarterly. Although they helped to inform this study through their
involvement with the wider steering group as they were involved in the initial discussions about the concept of the project, they had no further involvement in the research.

The purpose of this PhD research study was to explore the perceptions of adult field nursing students’ listening to people with dementia and their carers and to explore if, and how, this contact impacts on their thinking and practice. The research draws upon Sabat’s (1998) work on engendering personhood, by listening to people with dementia and exploring their individual life experiences. Findings will help to contribute to nursing knowledge and education, in a distinct way. Few studies could be found in the literature review in Chapter 2 that have given a voice to adult nursing students to learn first-hand the perceptions of their experiences of one-to-one interactions with people with dementia and their carers in their homes.

1.6 The Time for Dementia Programme

The *Time for Dementia* programme has been running since November 2014 and is an educational programme for undergraduate health professionals (Banerjee et al. 2016). It is intended that visits will serve as a foundation for healthcare students to explore dementia through listening to the experiences and perspectives of people with dementia and their carers. Funded by Health Education England in Kent, Surrey, Sussex, *Time for Dementia*, led by Professor Sube Banerjee, is a four year collaborative project involving Brighton and Sussex Medical School and the School of Health Sciences, University of Surrey. *Time for Dementia* aims to build on previous dementia healthcare educational programmes; The Buddy Program; Pairs Program; The TALES programme and The Duo Programme which utilise regular, recurrent placement visits to the same patients over a period of 12 months, to provide continuity of contact and opportunities to learn about dementia and patient experiences (Mohardt 2006, Jefferson et al. 2012, Mohardt et al. 2013). Programmes are summarised in Table 1 pg. 25 (Banerjee et al. 2016). *Time for Dementia* differs from these previous initiatives in that it has been made a core part of the curriculum as opposed to a voluntary option (Banerjee et al. 2016). Visits were integrated within clinical practice hours; students were allocated to visit a person with dementia and their carer 3-4 times in their own homes over a period of 2-3 years.
Table 1: Summary of Programmes

<table>
<thead>
<tr>
<th>Name of Programme</th>
<th>Source of Information</th>
<th>Student population</th>
<th>Schedule of Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Buddy Program (Northwestern University)</td>
<td>Mohardt et al. (2013)</td>
<td>First Year Medical Students</td>
<td>4hr/month</td>
</tr>
<tr>
<td>The PAIRS program (Boston University) (University of Kansas)</td>
<td>Jefferson et al. (2012) Mohardt et al. (2013)</td>
<td>First Year Medical Students</td>
<td>4hr/month</td>
</tr>
<tr>
<td>The TALES Program (Dartmouth University)</td>
<td>Mohardt et al. (2013)</td>
<td>First and second year medical student</td>
<td>2 visits/month (1hr)</td>
</tr>
<tr>
<td>The Duo Program (Washington University)</td>
<td>Mohardt et al. (2013)</td>
<td>First and Second year medical students</td>
<td>2hr/month</td>
</tr>
</tbody>
</table>

Longitudinal visits over three years offer adult nursing students a complementary approach to the traditional block placements often used in adult nurse education. Evidence suggests that such block placements alone do not provide an opportunity to develop comprehensive understanding of disease and the impact on the person, consequently nursing students rarely have more than a snapshot exposure to people with dementia (Banerjee et al. 2016).

As far as the researchers are aware this is the first initiative of its kind to be incorporated into both medical, nursing and paramedic programmes to provide a longitudinal experience of dementia. The visits are in line with the new Health and Social Care Act (2014) that aims to promote the well-being of people with dementia. As part of the project group, from its conception, I was involved in the development of the Time for Dementia project’s aims, objectives and measures (Banerjee et al. 2016).

1.6.1 Objectives: Time for Dementia Study

- to provide students with a longitudinal experience of a long term illness
- to improve students attitudes and knowledge of chronic illness and dementia
- to provide the opportunity for the mentor(s) to share their experiences of living as and with an older adult in the community with dementia
1.6.2 Healthcare Students

*Time for Dementia* was integrated into the 2014 and 2015 curricula for undergraduate nursing (adult and mental health field); paramedic students at the University of Surrey as well as second year undergraduate medical students at Brighton and Sussex Medical School (BSMS). Visits were mandated as part of students’ clinical practice hours.

1.6.3 Time for Dementia: Evaluation

The wider *Time for Dementia* programme involved a longitudinal cohort study using a mixed methods design, evaluating the impact on service users with dementia and their carers who are involved in the programme of visits as well as student participants (medical, paramedic, mental health and adult nursing students). Assessments of student participants occurred on an annual basis, a summary of these measures is included in Appendix 13. Similarly assessments of people with dementia and their carers occurred on an annual basis, using health-related quality of life measures DEMQOL (Smith et al. 2007), DEMQOL-Proxy (Smith et al. 2007) and Zarit Carer Burden Inventory (Zarit et al. 1980). Annual focus groups also occurred with people with dementia and their carers, evaluating the impact on their involvement in the programme (Banerjee 2016).

1.7 PhD study

This PhD is just one element of a wider evaluation for the *Time for Dementia* project. Individual lived experiences of dementia can be viewed as unique experiential knowledge, contextualised within a person’s own personal frame of reference, often not possessed by health professional educators. Utilising a qualitative approach, the overall aim of this PhD study was to explore the experiences of adult student nurses’ visits with people with dementia and their carers in their homes over the 3 years of their undergraduate nurse training. I wanted to explore first-hand with adult nursing students if and how listening to and observing the lived experiences of people with dementia and their carers impacted on them. A timeline was developed to identify tasks and focus research activities through each phase of the project, this was important working as a full time lecturer studying a PhD part-time to help to plan and prioritise my work load (Appendix 21).

As a member of the nursing teaching faculty in a Health Education Institute, it was important for me to explore with adult nursing students if the educational activity had any perceived impact. In doing so, the key themes arising from the emerging students’ perceptions as part of
the process of their contact with people with dementia and their carers, over 3 years would be identified and explored. As Tod (2006) suggests, longitudinal interviews have the capacity to capture evolving experiences over time. Therefore, the advantage of utilising a longitudinal element for this study meant that the study involved the same participants over time. As dementia is a progressive condition; the value of the longitudinal nature of visits is that they provide students with a unique opportunity to visit, as much as possible, the same person with dementia and their carer throughout the three years of nurse training.

Visits were developed in a bid to try to challenge the more conventional orientations of doing to and caring for (Aranda and Jones 2010:254), by encouraging adult nursing students to seek an understanding of the impact of living with dementia, through exploring the perspectives, experiences and feelings of people living with dementia and their carers. Arguably, in the absence of cure, the overarching principle of dementia care should be supporting people with dementia to maintain or improve their quality of life. The aim of the visits was to try to personalise nurse education by focusing on the lived experiences of people with dementia rather than on their diagnosis, to try to see the world from their perspectives. Squier (1998:128), suggests that listening to the perspectives of illness can help students’ to:

*Bridge the gap between knowing the facts about the disease and understanding the patient’s illness experience.*

Longitudinal contact over 3 years provided adult nursing students with an opportunity to establish a relationship with the person with dementia and their carer, thereby exposing them to any changes in their dementia journey. It was anticipated that through engagement with the person with dementia, exploring and observing relations with their carer, that students may gain an insight into the social and humanistic aspects of the person’s dementia experiences. As Robinson, Clare and Evans (2005:337) recognise, *dementia is not experienced by individuals in isolation*. Therefore inclusion of carers enabled students to explore how dementia impacts on a person’s relationships with others. Carers’ inclusion in the visits is a recognition of the importance of the nature of the relationship between the person with dementia and their carer. Dementia experts advocate that dementia care needs to be inclusive in its approach to understand the person with dementia in the context of their significant relationships (Kitwood 1997; Sheard 2004; De Vries, Drury-Ruddlesden and Gaul 2016).

Despite an abundance of literature relating to service user involvement in mental health and social work education programmes, the scoping review identified that there appears to be a lack of literature in relation to the involvement of people with dementia in adult nurse education.
Rhodes (2010) identified that there is a paucity of longitudinal studies to defend the development of service user involvement in the education of healthcare professionals. Few longitudinal educational programmes involving people with dementia were identified; and those only involved medical students over 12 months who volunteered to participate (Mohardt 2006; Jefferson et al. 2012; Banerjee et al. 2016). The scoping review of the literature in Chapter 2 (section 2.3) found no longitudinal studies that explored the impact of adult nursing students visiting people with dementia and their carers in their own homes. Adult nursing students are our registered nurses of tomorrow, therefore it is essential that they are adequately prepared to support people with dementia. Educational and experiential interventions are viewed, by many, as key to try and address the disinclination of some nursing students to work with older people in practice (Heliker et al. 1993; Haight et al. 1994; McKenzie and Brown 2014; Baillie et al. 2015). The career destination of adult nursing students is explored further in Chapter 2 (section: 2.18). Caring for older people living with dementia needs to be considered a core nursing role and central to adult nursing practice. It is estimated that one in four UK adult hospital beds are occupied by people over the age of 65 with dementia (Alzheimer’s Society 2009), as the population continues to age this figure will increase (Alzheimer’ Society 2014a). Consequently adult student nurses must be adequately prepared during their training to ensure they have a realistic understanding that their roles as registrants will involve caring for older people living with dementia (Baillie et al. 2015). To ensure that as educators we are preparing adult nursing students for practice, it is essential to research new educational interventions and their impact on preparing nursing students to support people with dementia. In one of my earlier memos I wrote:

*My research is timely as I want to explore how to integrate dementia in undergraduate nurse curricula - the driving force for change is the HEE mandate so there is an opportunity to fulfil the mandate in a meaningful way that makes a difference.*

To ensure a person centred approach to care, nurses have a role in supporting people with dementia to live full and active lives that enable and empower them. A series of high-profile national reports; including Willis (2012), Francis (2013) and Keogh (2013) have emphasised the need for care to be patient-centred. As Kenny (2004) asserts, educators can no longer be passive in their delivery of education, it is only by creating educational responses through innovative solutions that the ambition of promoting *high quality compassionate and culturally competent dementia care* can be achieved (DH 2016). Diachun et al. (2006) suggests that students remember 20 per cent of what is heard, 30 per cent of what is seen and 80 per cent of what is experienced. *Time for Dementia* visits aim to develop dynamic placement opportunities enabling students to share, through listening and observing, the *lived*
experiences of people with dementia and their carers, thereby creating a nurse curriculum that incorporates the experiences of the dementia journey. This biographical approach provides people with dementia and their carers with opportunities, if they desire, to talk about their life experiences, enabling students to explore their past and present lives with them.

1.8 Theoretical Location: Constructivist Grounded Theory Approach

Constructivist grounded theory provided a suitable ontology for this research to understand and explore adult nursing students’ experiences and perceptions of their visits. It was important to me that I chose an approach that recognised students as active participants in the research process, through meaningful involvement. Therefore the adoption of constructivist grounded theory was appropriate, as its strength is that it would allow the common themes and perspectives, articulated by the adult nursing students to emerge from the data. Charmaz (2006:10), suggests that grounded theories can serve as, a way to learn about the worlds we study. Supported by Strauss and Corbin (1998:12), who asserts that it can offer insight, enhance understanding and provide a meaningful guide to action. According to Charmaz (2006), a grounded theory approach can foster openness and understanding of participants’ meanings and actions, and has the potential to help transform practice. The research approach chosen for the study is explored further in Chapter 3.

1.9 Reflexivity: Situating Myself in the Research (Personal Context)

It is important to identify the personal paradigm or epistemological stance within an enquiry (Carr and Kalmbach Phillips 2010). As Charmaz (2006:6) proposes:

*The research journey begins before the traveller departs*

Acknowledging my background in dementia nursing and current position within nurse education is important within the research process, enabling me to explore my actions. I have a professional interest in undergraduate nurse development of dementia care. Mills, Bonner and Francis (2006:9) emphasise that, the relevance of biography is essential to a constructivist approach. Although there appears to be general agreement in the literature that the overall objective of reflexivity is to increase transparency and trustworthiness of qualitative research; there appears no consensus in defining the term (Finlay 2002; Mruck and Mey 2007; Doyle 2012). Hertz (1997:8) defines reflexivity as:

*Intensive scrutiny of “what I know” and “how I know it” ...to provide insight on the working life of the social world and insight on how that knowledge came into existence.*
As a novice researcher this definition by Hertz (1997), helped me to develop my understanding of reflexivity.

Many authors suggest that reflexivity encourages researchers to acknowledge the integral part they play in the social world being studied, arguing that this is important to the research process as it provides validity to findings (Gerrish and Lacey 2006; Bishop and Shepherd 2011; Coughlan and Brannick 2012; Engward and Davies, 2015). Some authors have expressed concern regarding what they view as excessive reflexivity, warning there is a risk of shifting the emphasis of the research by focusing too much on the researcher, thereby risking losing the voice of the participant (Finlay 2002; Cutcliffe 2003; Bishop and Shepard 2011; Holloway and Bily 2011; Doyle 2013). Bishop and Shepard (2011) terms this as self-indulgence on the part of the researcher, suggesting that in order to try and avoid self-indulgence, researchers need to continually examine their personal subjectivity through ongoing reflexivity. On the other hand Ortlipp (2008), suggests that reflexivity provides a means of communicating feelings and opinions of the researcher to make them more visible. This correlates with Holloway and Biley (2011), who emphasise that the importance of balancing knowledge of ourselves and being reflexive is more about being thoughtful about our position and identity as a researcher.

Engward and Davis (2015) emphasise that reflexivity is essential in any qualitative research, especially grounded theory, as researchers need to make the decisions they make transparent to establish credibility. They contend that data does not stand alone and emergent analysis could depend on what data the researcher considers credible, which they argue, may be framed by their presuppositions. As advocated by Charmaz (2006:15), it was essential for me to consider what I brought to the scene, what I saw and how I saw it. Additionally Charmaz (2006:10) reflects that, as researchers:

*We construct our grounded theories through both our past and present involvement and interactions with people, perspectives and research practice.*

Early in the research process, I acknowledged that I would not be able to disassociate myself from who I am. My professional background is that of an adult registered general nurse, practice developer, dementia specialist nurse and current role as a nurse lecturer working in a university. The majority of my nursing career has been spent working with older people in a variety of settings. Although nurses have always been required to demonstrate their competence (NMC 2015), as a ward sister, I wanted to be seen as a clinical expert and so began my journey into higher education, eventually making the move to work in practice development. After completing a BSc in Clinical Practice (Care of the Older Person) and PG
Diploma (Master of Science), I became a dementia specialist nurse working in acute care. The shifting landscape of the structural and funding changes of the NHS opened up opportunities for me to help prepare students to meet the current and future needs of people with dementia, I became a dementia teaching fellow in higher education and during my PhD study I was promoted to lecturer in older adult care.

As Alvesson and Stoldberg (2000) contend, researcher motivation is a vital aspect of research. From the start of this process I was conscious that because of my background in dementia, nursing and education, that I did not come to the research value-free. I am committed to a philosophy of caring and working with people with dementia in a way that builds on their strengths. Each person's experiences of dementia is unique and contextualised within their personal frames of reference, and in my experience learning can be gained through our interaction with others. I began the PhD process by reflecting on my own lived reality and experiences, as well as my world view in order to explore and my attitudes and values within the research process and choice of research paradigm (Denzin and Lincoln 2005). The constructivist interpretative paradigm chosen assumes a relativist ontology whereby many realities and meanings are developed through experiences of interactions with others.

Reflexivity involved constant examination and increasing awareness of the potential for my influence on the choice of methodology, data collection, interpretation and analysis. As Woodthorpe (2009) suggests, the process of reflexivity offered an opportunity for me to account for my interpretations, enabling me to reflect on any success and failures which I found was an important component of doing a longitudinal study over 3 years. I also engaged regularly with my supervisors, other experienced researchers as well as other post graduate students to discuss my research and share their views and opinions. Koch and Harrington (1998:888) refer to this process:

As a critical gaze turned toward self to aid examination of personal position, identity and self.

Although some researchers prefer the use of third person in academic writing, I reflected early on in my research journey that writing in the first person was consistent with the constructivist grounded theory approach that underpins my research. As Charmaz (2006:175) emphasises:

Voice echoes the researcher’s involvement with the studied phenomena.
Figure 1, illustrates the supportive constructs utilised to try to increase reflexivity, central to this construct were my memos and reflective journal which were kept throughout my research journey.

**Figure 1: Supportive Constructs Utilised to Increase Reflexivity:**

1.10 **Research Journal**

As a novice PhD researcher, keeping a journal provided a research trail that enabled me to critically reflect on the processes of my research journey and practice throughout my research. I recorded my decisions, thinking and experiences to help me to make sense of my actions, as well as increasing transparency. Keeping a journal promoted a sense of perspective as I am by nature a perfectionist and critical of my work. I was conscious at the start of my research that although my professional experiences may enhance my sensitivity to the data and analysis, I did not want my insights to prevent me from identifying different perspectives that I
may miss. As my research was predominately interview-based, this meant that I was the main instrument in the data collection. Critical reflection led to changes being made in my approach to interviews as reflected in one of my memos (Appendix 18). Being transparent in my decision making throughout the research process and checking with my supervisors, I hoped to be able to identify any preconceptions that may be imposed.

1.11 Summary

Chapter 1 has presented an introduction to the research study. The research design chosen places adult nursing students at the centre of the research to explore their perceptions of visiting people with dementia and their carers in their own homes. This study contributes to nursing knowledge and education in a distinct way. Few studies could be found that have given a voice to adult nursing students and enable them to learn first-hand how they perceived their experiences of one-to-one interactions with people with dementia and their carers affected their thinking and practice.

The next Chapter explores the context of people with dementia in society, healthcare and education. It examines the background and provides rationale for undertaking the study at this time and explores the role of literature in grounded theory study. A scoping review that explores existing research regarding the involvement of service users with dementia in adult nurse education is conducted to define existing parameters to identify current knowledge and provide a frame and rationale for the research. The review highlights what previous research has covered as well as identifying where knowledge gaps existed.
Chapter 2: Initial Literature Review

To learn is to participate and contribute to the evolution of communal practice.

(Kleiny 2002:208)

2.1 Introduction

This Chapter explores the context of people living with dementia in society, healthcare and education. It examines the background and provides rationale for undertaking the study. The role of literature in grounded theory study is explored prior to discussing the context of people with dementia and the theories of dementia. A scoping review of the involvement of service users with dementia, in undergraduate adult nurse education, was undertaken to define the existing parameters and provide a frame for the research by identifying existing knowledge and a rationale for the research. The perceptions of adult nursing students working with older people and dementia as well as the potential impact on career destination is also explored.

2.2 Use of Literature in a Constructivist Grounded Theory Study

The role of the literature review in grounded theory is frequently debated in relation to the extent to when it should be incorporated into grounded theory (Elliott and Jordan 2010; Dunne 2011; Giles et al. 2013). Traditional or classical grounded theorists contend that literature reviews should be carried out after the completion of data analysis (Glaser and Strauss 1967). This, it is argued, prevents the researcher from imposing existing theories or knowledge and contaminating the analysis of data and concepts (Glaser and Strauss 1967). Supported by Glaser (1998) the intention is to avoid importing pre-conceived ideas and imposing them on the research. However, Glaser and Strauss (1967), acknowledge that no researcher enters the field of research with a blank slate. Heath and Cowley (2004) and Suddaby (2006) both support this view, arguing that it is unrealistic for researchers to approach their research unaffected by past experiences and knowledge. Proponents of constructivist grounded theory argue that the literature review informs the construction of knowledge, which should be woven into the research (Charmaz 2006; Mills, Bonner and Francis. 2006). Moreover Charmaz (2006), argues that the traditional approach actually prevents the researcher from seeing the data through the lens of earlier ideas. This view is supported by Urquhart (2007), who asserts that rather than prejudicing the researcher, reviewing the literature is effective in helping to orientate them to the field of study.
Even though the nature of the study had been determined; in keeping with a constructivist
grounded theory approach, an initial review of the literature was performed as advocated by
Charmaz (2006:166), outlining the path to reviewers. A broad early scoping review of the
literature surrounding service user involvement in undergraduate adult nurse education was
undertaken, and provided a context through defining the existing parameters of the research
and general issues related to the research area. As Hutchinson (1993) and Levac et al. (2010)
acknowledge, it can also identify where knowledge gaps exist. Armstrong et al. (2011), contend
that scoping reviews do not aim to critique and review the quality of the evidence base, instead
they help to identify the breadth of evidence. The scoping review provided a frame for the
research identifying existing knowledge in the field and provide a rational for the research.
Furthermore it informed the research proposal, which was a prerequisite for ethical approval,
and afforded a significant contribution to understanding the current knowledge surrounding the
topic. The scoping review identified scant literature on educational interventions involving adult
nursing students and people with dementia and their carers, thus strengthening the impetus
and rationale for the PhD study. References were stored through use of RefWorks; a
bibliographic management product. Critical appraisal skills programme (CASP) ten criteria for
assessing research evidence (CASP 2016) was used as a framework to judge the quality of
the literature and their inclusion in the initial review.

As the theory developed a more detailed literature review was undertaken and appropriate
literature was analysed throughout the study. Relevant literature was included as a source of
data; woven into the discussion and compared with the data generated throughout the study
(Figure 1, pg. 31). In keeping with the constructivist grounded theory approach, as advocated
by Charmaz (2006), any points of convergence and divergence with existing literature are
discussed within the context of the findings of this study.

2.3 Scoping Review: Evaluation of Service User Involvement in Pre-Registration
Adult Nurse Education.

The scoping review aimed to address the following broad question:

What is the impact of service user involvement on pre-registration adult nurses?

Searches were conducted using Surrey Search, the University of Surrey on-line search
platform which enabled a systematic search of databases; CINAHL; MEDLINE; Cochrane;
Educational Research and Web of Science. The search was based on research published from
1996 to May 2017. Searches were limited to peer-reviewed English language literature, the
inclusion and exclusion screening criteria utilised is summarised in Table 2. The last date that the search was performed was 31st May 2017, details of the search are summarised in Appendix 1. Studies were also identified through snowballing and hand searching reference lists of included papers. Papers which did not involve service users in pre-registration adult nurse students were excluded.

Table 2: Inclusion and Exclusion Criteria

<table>
<thead>
<tr>
<th>Category</th>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Search of database</td>
<td>English language</td>
<td>Non-English language</td>
</tr>
<tr>
<td></td>
<td>1996 onwards. Last date of search 31.05.17</td>
<td>Pre-1997</td>
</tr>
<tr>
<td></td>
<td>No limits – geographical location</td>
<td>Non-peer reviewed</td>
</tr>
<tr>
<td></td>
<td>Peer reviewed</td>
<td></td>
</tr>
<tr>
<td>Population</td>
<td>Adult undergraduate or pre-registration student nurses</td>
<td>Non adult undergraduate or pre-registration student nurses.</td>
</tr>
<tr>
<td></td>
<td>Post-registered nurses (qualified)</td>
<td>Post-registered nurses</td>
</tr>
<tr>
<td>Intervention</td>
<td>Service user, patient or client involvement in adult nurse education</td>
<td>No evidence of service user, patient or client involvement in</td>
</tr>
<tr>
<td></td>
<td></td>
<td>nurse education</td>
</tr>
<tr>
<td>Outcome</td>
<td>Educational activity – educational delivery in classroom or practice</td>
<td>No evidence of educational activity</td>
</tr>
</tbody>
</table>

2.4 Search Results

261 records were retrieved through searches and screened for relevance using the inclusion and exclusion criteria (Table 2). Of these 45 papers were excluded through duplication. A further 8 papers were found through hand searching and snowballing. A total of 224 papers were screened resulting in 183 papers being excluded as they did not meet the inclusion/exclusion criteria. Of the 41 papers reviewed only 9 reported evaluations of older service users involved in adult nursing programmes; although none of the studies specifically involved older people with dementia. Figure 2 (pg. 36), illustrates the search process.
Only 9 studies were selected for the review, study characteristics and findings of the selected papers are summarised in Appendix 2.

**Figure 2: The Search Process**
2.5 Summary of Study Characteristics

Of the 9 studies selected, 7 involved evaluations of service user involvement in nursing programmes, only 4 of the studies involved adult nursing students and older people. The remaining 2 were descriptive studies of service user engagement initiatives in nurse education (Speed et al. 2012; Torrance 2012). Although Speed et al. (2012), did not specify a specific field of practice, the decision was taken to include it in the review, as views of both lecturers and service users were explored on the involvement of service users in nurse education.

All of the studies reviewed were small scale, exploratory or pilot, conducted in a single university setting, thus limiting the scope for generalizability. The dominant methodology was qualitative \((n=4)\), utilising interviews and focus groups (Christiansen 2011; Speed et al. 2012; Torrance 2012; Gidman 2013). 2 of the studies used a quantitative approach (Costello and Horne 2001; Ryan, Melby and Mitchell 2007). Both Reitmaier et al. (2014) and Retimaier Koehler et al. (2016) utilised an illuminative evaluation approach involving semi-structured interviews and reflective journals to evaluate their education programme. Developed by Parlett and Hamilton (1972) to evaluate education programmes, illuminative evaluation approach incorporates a range of methods to explore, describe and interpret what it is like to participate in a programme. Basran et al. (2012) utilised a mixed method approach to collect both quantitative and qualitative data.

2.6 Discussion of Findings

2.6.1 Ways in which Service Users are Involved in Student Nurse Education

Despite all the various drivers calling for greater service user involvement in adult nurse education it was surprising that only limited empirical research met the eligibility criteria for the literature review. Review of the retrieved studies found only 9 that focused on how the perspectives of service users were incorporated into adult pre-registration nursing programmes (classroom or practice). The review identified that service users were involved in the delivery of adult nurse education in a variety of ways. Costello and Horne’s (2001) study was the only study to involve face-to-face service user involvement in classroom teaching. Both Christiansen (2011) and Gidman (2013) reported using service-user led virtual learning digital resources. Whilst Speed et al. (2012) explored both lecturers and service users’ perspectives of service user involvement in nurse education, Torrance (2012) explored the perspectives of lecturers only.
Although no retrieved studies could be found in the search that involved adult nursing students visiting older adults with dementia and their carers as part of their curriculum, 4 of the reviewed studies involved nursing students visiting ‘well’ older people in the community (Ryan, Melby and Mitchell 2007; Basran et al. 2012; Reitmaier et al. 2014; Reitmaier Koehler et al. 2016). Ryan, Melby and Mitchell (2007) study involved adult nursing students identifying a well-older person (neighbour, family friend), over the age of 65 years to visit in Year 1 of their curriculum. Similarly a study by Basran et al. (2012) involved students (pharmacy, medical, nutrition, physical therapy and nursing), visiting older people over a semester (visit n=4) as part of a senior mentoring program. A more recent study by Reitmaier et al. (2014) and Reitmaier Koehler (2016); involved nursing students’ visiting older adults as part of a standalone gerontological course over one semester (visit n=5).

2.6.2 Benefits and Limitations of Service User Involvement

The reviewed studies identified a range of benefits and challenges for service user involvement in nurse education, from a range of different perspectives including nursing students, service users and lecturers. The majority of the studies (n=7), reported that students gained greater insights of service users experiences of illness and perspectives of care (Costello and Horne 2001; Ryan, Melby and Mitchell 2007; Christiansen 2011; Basran et al. 2012; Gidman 2013; Reitmaier et al. 2014; Reitmaier Koehler et al. 2016). Findings of these studies suggest that nursing students found their experiences of service user involvement as transformative, stimulating critical reflection on behaviours in practice enabling many to move towards seeing beyond the clinical aspects of the nurse’s role. Although Gidman (2013) reported that students in their study articulated learning from their experiences of listening to digital stories, there was no evidence of action or impact on practice reported as a result of listening to service users’ stories. Hence, it could be argued that the approach of using digital stories does not establish relationships, which may help students to connect and better understand individual needs. Therefore the use of digital stories and case studies could be perceived as second hand presence, and therefore have less veracity and authenticity, even though they are based on a person’s lived experience.

Studies of service user involvement, focusing specifically on older adults, reported that most of the students’ felt that they had gained a much better insight into the perspective of the older person (Costello and Horne 2001; Christiansen 2011; Basran et al. 2012; Reitmaier et al. 2014; Reitmaier Koehler et al. 2016). Costello and Horne (2001) suggest that service user
engagement is about changing students focus from one of passive learning to actively engaging with service users in order to develop their understanding. This was reflected in their findings which reported that students found the discussion element of the session the most informative. However, Torrance et al. (2012) and Speed et al. (2013), highlighted concerns involving service users in education. They identified that lecturers reported challenges concerning resourcing and logistics of preparation and support of service users during and after the sessions. Although some of the factors identified by Torrance et al. (2012) and Speed et al. (2013), may be contributory factors to the lack of service user engagement in nurse education identified in this review, further research is required.

Christiansen (2011) explored the impact of listening to service users experiences, and if and how, it influenced professional learning in third year students. She identified that stories provoked strong emotional reactions in the students. Similarly Costello and Horne (2001), evaluated the impact of listening to the stories of service users in the classroom. They found that students’ valued listening to the perspectives of service users care experiences, thereby reinforcing the importance of person centred care. Costello and Horne (2001) findings suggest that nursing practice could be improved by developing students’ understanding of service user and carer experiences from their perspectives. They reported the value of listening to patients about their problems to gain an insight into their experiences of care. Their findings suggest that service user involvement in education helped to bridge the gap between theory and practice by enabling students to gain insights into their experiences and making it real. Christiansen (2011) and Gidman (2013) also reported that service users were a valuable source of knowledge, helping students to understand alternative perspectives of care, bringing insights that enriched their educational process. Similarly Christiansen (2011), also reported that service user involvement helped students to capture the essence of person/family-centred care as opposed to professionally focused care. A criticism of both Christiansen (2011) and Gidman’s (2013) studies is that despite articulating that students’ learned from their experiences, there was no evidence of action or reflection reported as part of their findings.

Only 2 of the studies explored the sustained impact of service user involvement a year after the educational intervention (Ryan, Melby and Mitchell 2007; Basran et al. 2012). Ryan, Melby and Mitchell’s (2007), used Kogan’s attitude towards older people scale, to explore the impact of visits to well older people in the community over one year. Adult nursing students were tested at the beginning of their degree programme (n=130) and again one year later (n=94) following their visits to well older people in the community. Although results found no statistical
differences pre or post intervention in attitudes, they reported that nursing students had positive attitudes towards older adults at the start of their programme which was sustained a year later. It could be argued that nursing students sustained their positive attitudes towards older adults as a result of their experiences of their visits to older adults. Basran et al. (2012) study also used a pre and post survey, using Polizzi ageing semantic differential and focus groups; as well as an online survey to follow up students a year after the intervention. The findings of Basran et al. (2012) contrasted with Ryan et al. (2007), as they reported that students’ perceptions of older people improved significantly and this was sustained after one year post intervention. However, they only had a 44.3 per cent response rate at follow up which is lower than the recommended rate of response of between 70-80 per cent (Millar and Dillman 2011).

Both Ryan, Melby and Mitchell (2007) and Basran et al. (2012) acknowledge in their findings that attitudinal change is complex to measure as other variables may be involved other than the intervention under investigation. A criticism of both studies is that no examples of action as a result of their experiences or changes to practice were reported in either of the studies. Moreover no control group was included as a comparison. Although findings from both studies indicated that positive attitudes remained throughout the first year in pre and post intervention students, it was not clear if this was sustained as there was no longitudinal impact reported after this.

Only 4 of the studies, found in the literature search, involved adult nursing students visiting older people in the community (Ryan, Melby and Mitchell 2007; Basran et al. 2012; Reitmaier et al. 2014; Reitmaier Koehler et al. 2016). Reitmaier et al. (2014) explored the experiences of two cohorts of students (n=32), visiting older adults in the community (assisted living). Results suggested that students valued the relationships they formed with older people, reporting an increased understanding of the human experiences of ageing. Ryan, Melby and Mitchell (2007); Basran et al. (2012) and Reitmaier et al. (2014), incorporated reflective journals in their studies to enable students to capture their experiences with older people. Students’ reported that they valued the relationships they developed with older people they visited, as well as demonstrating an increased understanding of ageing on the person. Both Basran et al. (2012) and Reitmaier (2014) reported that students recorded that they found their visits enjoyable and valued their relationship, identifying that they had learned more about the impact of ageing than they had through traditional education. In a subsequent study, Reitmaier Koehler et al. (2016) explored the experiences of a total of 266 nursing students from 3 cohorts of nursing students. Although results indicated an overall significant increase (p=0000) in positive perceptions of nursing students’ working with older adults, there was no evidence that this was
translated in their chosen career choices. Although findings from reviewed studies involving visits to older people all reported that nursing students felt that their communication skills had improved as a result of their visits, there were limited examples that reflected how and if this was translated into practice.

Researchers were involved in the educational issue being investigated in 5 of the studies reviewed, which arguably gave their perspectives primacy (Ryan, Melby and Mitchell 2007; Basran et al. 2012; Gidman 2012; Reitmaier et al. 2014; Reitmaier Koehler et al. 2016). Unfortunately the other 4 reviewed studies did not indicate the role of the researcher(s) in the intervention being investigated, so they could also have been educators involved in the intervention (Costello and Horne 2001; Christiansen 2011; Speed et al. 2012; Torrance 2012). Only Basran et al. (2012); Reitmaier et al. (2014) and Reitmaier Koehler et al. (2016) discussed integration of the visits within the nursing curriculum. Although Basran et al. (2012), discussed integration of their shadowing program in the curricula for medical, nutrition and pharmacy students, interestingly participation was voluntary for adult nursing students. It was not possible to determine whether the other studies reviewed were one-off projects or integral to the curriculum.

2.7 Gaps in the Evidence Base

Only limited studies met the eligibility criteria of this scoping review of service user involvement in pre-registration adult nurse education. The lack of evidence of service user involvement in adult nurse curriculum was surprising given that the involvement of service users in curriculum delivery is a compulsory requirement of programme approval in the UK (NMC 2010). This finding contrasts with service user engagement in pre-registration mental health nurse education which is well-established (Terry 2012; Perry et al. 2013; Happell et al. 2014). The scale of adult nursing numbers are significantly larger than mental health students, which may be a contributory factor, as this may create logistical issues in the implementation of service user involvement in adult nurse pre-registration education compared to mental health. No longitudinal studies were found in the search of published literature that focused specifically on the impact of service users with dementia in adult nurse pre-registration programmes.

2.8 Summary of Scoping Review of the Literature

The focus of this review on the impact of service user involvement on adult nursing students’ education is unique, the paucity of literature identified in this review is surprising considering
service user involvement in adult nurse education has been mandated by the NMC (2010). Findings from the studies reviewed suggest that students found the experience of service user involvement transformative; capturing person centred care that enabled them to see beyond clinical aspects. Although only four of the studies reviewed involved older people (Ryan et al. 2007, Basran et al. 2012; Reitmaier et al. 2014; Reitmaier Koehler et al. 2016), students’ reported that engagement with older people in their learning appeared to evoke authentic connections and increased their knowledge of aging. Albeit limited, findings of the review support policy initiatives that service user participation in education focuses students’ learning on practice person centred care (DH 2010a).

Although the majority of the studies reviewed were small-scale qualitative studies, they still provided data that helped to inform and inspire this study, however, it is acknowledged that a limitation of the reviewed studies is that generalisability is not possible. The literature review exposed a lack of theory of service user involvement of people with dementia in adult nurse education. Literature evaluating the effects of involvement of older adults with dementia in adult nurse education is limited and further reinforced that a grounded theory methodology may be compatible with the area to be researched. Whilst the literature review supports that students’ gain from hearing the lived experiences of service users, to date this has not widely involved people with dementia or adult nursing students. Morse (2003:841), likened this situation to a skeletal framework, where some of the characteristics have been identified but further research is required to:

Flesh out...the conditions, circumstances, variations and interrelations of the characteristics that surround the structure, to build theory.

2.9 Locating Older People with Dementia in Society and Healthcare.

As identified in Chapter 1, dementia is an important health and social care problem nationally and internationally. The Nursing and Midwifery Council (NMC) (2015), who are responsible for the regulation of nurses and midwives in the UK, requires that nurses treat people as individuals. Buber’s (1970) concept of genuine dialogue and working with older people as people, has been hugely influential on nursing and informs the philosophical position of relationship in this study (de Vries 2004; McCormack and McCrance 2010; McMahon and Christopher 2011). According to Buber (1970:62):

Actual life is encounter and takes place in a relationship of genuine dialogue in which each person looks towards the other in a mutual relationship of reciprocity and openness.
Buber (1970) argues that listening is essential which he terms an, *I-Thou relationship*. In contrast he suggest that an *I-It* relationship is one which a person does not listen and treats another as an object. He describes relation as *in flux* as there are occasions where nurse interactions characterising an *I-It* relationship occur if diagnosis or physical needs become paramount to sustaining life. At other times, he suggests that the genuine dialogue of *I-Thou*, that nurtures a trusting relationship affirms that the personhood of the patient can be developed. Kitwood (1997) used the relationship of *I-It* to illustrate how people with dementia are often objectified, arguing that through genuine interaction of being treated as a person that they can experience genuine interaction of *I-Thou* relationship, capturing the uniqueness of their being (Kitwood, 1997:43).

2.10 Perspectives of Dementia

There are different approaches to understanding dementia: personhood, social disability and citizenship, their models are explored as each offer contributions that can reflect how to understand and respond to people with dementia.

2.11 Personhood and Person Centred Care

The National Institute for Health and Clinical Excellence (2006:11) support the principles of person centred care, advocating that:

*NHS Trusts provide services that address the personal and social care needs and mental and physical health of people with dementia.*

This person centred focus was reinforced in the National Dementia Strategy (2009), Prime Minister’s Challenge (DH 2012) and more recently the Prime Minister’s Challenge on Dementia 2020 (DH 2016).

Biomedical definitions of dementia fail to incorporate the impact of factors, such as the social context of the person (Sabat and Galadstone 2010; Fox et al. 2013). Boyle (2000) suggests that biomedical understanding of dementia often results in a person with dementia being viewed in a state of decline, rather than as a person with remaining potential. McCormack (2004) argues that this may result in the person being treated as *things* rather than as a person (McCormack 2004). Kitwood (1997) further challenged the prevailing reductionist biomedical view of dementia by emphasising the importance of seeing the person and not just the disease, arguing that the disease is only one aspect of their lives. There is increasing emphasis on focusing on *seeing the person behind the patient* (Clarke et al. 2003; Sabat and Gladstone
In order to achieve this Kitwood (1997), emphasises the importance of therapeutic relationships in maintaining personhood, summarising personhood as:

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

Although this definition is accepted, in the main, uncritically; Dewing (2008) argues against personhood being seen as being bestowed by others, suggesting instead that it should be seen as a moral concern for others (Dewing 2008:10).

Since Kitwood’s (1990;1993) early work on person centred care the concept has been explored, debated and developed by many in the nursing field of dementia care (Brooker 2004; Dewing 2004; McCormack 2004; Nolan et al. 2004; Sheard 2004; McCormack and McCance 2006). Several frameworks with common themes have been developed to support person centred care in clinical practice: Senses Framework (Nolan et al. 2004), VIPS Framework (Brooker 2004) and Person centred Nursing Framework (McCormack and McCance 2006). McCormack (2004) suggests that the recurring themes are: knowing the person, values, biography, relationships and authenticity. One way that this can be achieved is by listening to the person living with dementia in order to understand the subjective experience of the person.

Mead and Bower (2000) define patient-centred care as multidimensional, suggesting it has five key aspects, or dimensions: bio psychosocial, patient as person, sharing power and responsibility, therapeutic alliance and doctor as person. Arguably the doctor as person dimension can relate to any health care practitioner such as nurse as person. Educational approaches, such as Time for Dementia visits, that focus on direct interactions aimed at getting to know the person with dementia, is one approach to potentially develop patient centeredness in adult nurse education. Lislerud Smebye and Kirkevold (2013) suggest that in dementia, personhood is increasingly concealed rather than lost, Dewing (2008) supports this, arguing that to maintain personhood practitioners need to enter into partnerships to assist and maintain identity and worth. Hence practitioners need to know more about the person to allow them to: provide care and services that are compatible with the individual’s values and which are, as such, highly valued (Ford and McCormack 2000:42).

Both Adams (2001) and Dewing (2008) criticise Kitwood’s work on person centred care for failing to include families and carers a well as healthcare staff. Keady et al. (2012:156) also criticises the philosophical underpinnings of person centred care for remaining at the level of the individual; arguing that this fails to locate people with dementia as an active participant in
their community/neighbourhood. This view is supported by Bartlett and O’Connor (2007), who suggest that broadening the focus from personhood to citizenship could help people with dementia connect to their wider society.

2.12 Social Model of Disability

Hulko (2004:238) extended the concept of person centred care to include the focus on the identity of individuals, highlighting the increasing amount of research that aims to understand the experiences of people with dementia individually and in relation to others. Her work recognises the importance of knowing where each person is located socially within their different identities and the broader environment. Many dementia experts suggest that a social model of disability may provide a framework to not only aid a better understanding but also challenge assumptions towards dementia (Barnes 2003; Bond 2004; Marshall 2004; Oliver 2004). Proponents of the social model suggest that people with dementia are socially disadvantaged by negative responses in the way that society treats or excludes them, rather than their impairments (Finklestein 2001; Oliver 2004; Marshall 2005). Furthermore Oliver (2004:21) suggests that this exclusion may result from a lack of understanding rather than prejudice citing the negative images in the media – films, television and newspapers.

The social model emphasises that dementia is not the fault of the person and the focus is on the skills that the person retains rather than on their losses. Gilliard et al. (2005) suggests that it is the responsibility of those who do not have dementia to reach out to people with dementia. The Mental Health Foundation (2015:21) states that:

A social model approach argues that people with dementia must be viewed as a legitimate part of mainstream society, living in communities as equal citizens with their value recognised and respected.

Through viewing the person with dementia within the context of their social circumstances and biography, the social model of care tries to understand emotions and behaviours of the person, in doing this, care and support can be designed to meet the individual needs of the person.

2.13 Citizenship

Proponents for developing a citizenship model of dementia to empower people with dementia, argue that otherwise their voices may be lost in the practice of caring (Bartlett and O’Connor 2007; Baldwin 2008; Brannelly 2011). Baldwin (2008) contends that narratives such as stories are linked to citizenship. Consequently models of partnership education that utilise personal narratives may help to contribute to re-valuing people with dementia in society. As Francis
(2013) emphasised, patient experiences must be at the centre of care. Bartlett and O’Connor (2007) highlight that anyone may experience dementia in the future, arguing that the citizenship model of dementia expands the focus from the individual, encompassing social inclusion and rights. Wallcraft, Read and Sweeney (2003) suggests that the citizenship model is in keeping with the survivors’ movement of mental health services. It could be argued that involving people with dementia in education changes their role from passive recipients of services to active citizens.

2.14 Social and Political Drivers to Improve Dementia Care

The World Health Organisation’s report *Dementia: A Public Health Priority* published in 2012, frames dementia as a social, economic and health burden in society. Despite the inclusion of the need to tackle stigma and develop a dementia friendly society, the report, unfortunately, seems to take more of a medicalised approach to dementia in terms of disease burden.

In recognition of dementia as a significant global public health concern, especially as our population ages, it has been declared a national priority in the UK. Some studies have suggested that the prevalence of dementia is significantly lower in the UK than originally predicted (Banerjee 2013; Matthews et al. 2013; Wu et al. 2015). In fact Wu et al. (2015) contend that predictions of a dementia epidemic as the population rises are overblown, arguing that the numbers of people with dementia is in fact stabilising. Banerjee (2013:1835) cautions:

*Even with a small decrease in incidence and prevalence, population ageing will still double the numbers with dementia worldwide in the next generation.*

The importance of bringing the *patient* back into the centre of health care policy and delivery, was emphasised in the Department of Health *Equality and Excellence: Liberating the NHS* with the strapline: *Nothing about me without me* (DH 2010a). Dementia is often described as a social death, this is reflected in a study by Sweeting and Gilhooly (1997) who in interviews with 100 carers, found that over a third of carers believed and behaved as if the person with dementia were socially dead. They asserted from their evaluation that:

*Society may view or treat the dementia sufferer as a limited or non-person who is demonstrably making the transition from life to death* (Sweeting and Gilhooly 1997:99).

Moreover Brannelly (2011) argues that practitioners who are unable to see a person with dementia as socially alive are unable to engage and facilitate personhood when providing care. In accordance with social justice, the human rights of people with dementia should be recognised; making sure they are valued in the same way that people without dementia are
valued, thereby ensuring systems of care, education and policies support this. Since the launch of the National Dementia Strategy (DH 2009b), there have been various national initiatives aimed at improving dementia awareness and dementia care. In 2012 the Prime Minister launched his three year dementia challenge, it provided significant impetus to address the need to improve dementia care (DH 2012). A further Prime Minister’s Challenge 2020 continued this impetus to improve dementia care and healthcare education, pledging that all NHS staff, including undergraduate healthcare professionals, would undergo dementia training (DH 2015).

2.15 Stigma of Dementia

*The most terrifying illnesses are those perceived not just as lethal but as dehumanising, literally so…* (Sontag 1994:124)

Brooker (2004:217) refers to the stigma that surrounds older people with dementia as *dementia-ism*; which she argues is a further barrier to achieving person centred care at a societal level. Robertson (1990:436) describes dementia as constructed as, a *fearsome disease, surrounded by images of the loss of qualities that represent humanness.* Whilst Graham et al. (2003) contend that dementia should be viewed as one of the most stigmatised conditions of older age. Forty per cent of people with dementia in a survey by Alzheimer’s Disease International (2012) reported suffering from stigma and isolation. People with dementia are often labelled as *victims or sufferers* and according to the World Alzheimer’s Report (2012) dementia is feared more than any illness among the over 55s. Fear of dementia is also reflected in a YouGov survey of over 2000 people in the UK which highlighted that more people feared dementia (34%) than feared death (18%) (Alzheimer’s Research 2011). The Alzheimer’s Society (2014b), suggest that negative attitudes within society continue to pose barriers to people living well with dementia. Initiatives such as dementia friendly communities have been developed to try and raise public understanding of dementia and try to reduce stigma (Alzheimer’s Society 2013). Kate Swaffer (2015), a person diagnosed with younger onset dementia asks us to, consider the phrase suffering from dementia vs diagnosed with dementia; arguing the first is negative and disempowering. Similarly Christine Bryden (2015:224), who also has dementia argues that sufferer is depersonalising; contributing to the stigma surrounding dementia.

Reducing stigma was one of the key objectives of the National Dementia Strategy (2009b). Debate about the term dementia has been subject to criticism; leading the American Psychiatric Association (2013) to refer to it as *major neurocognitive disorder* in their Diagnostic
and Statistical Manual (DSM-5). This led some to question if the word dementia has had its
day; arguing that it should follow neurosis into classification oblivion especially as it means out of one’s mind (Kurz and Lautenschlager 2009; Sachdev et al. 2014). In 2004 Japan changed their term for dementia from Chio due to its negative connotations (foolish, stupid, absent minded) to Ninchisho (cognitive impairment) (Miyamoto, George and Whitehouse 2011). Sachdev et al. (2014) argue that the limitations and disadvantages outweigh any usefulness that remains in the term dementia suggesting that all causes of dementia are established diseases in their own rights and do not require the appellation of dementia. Conversely Sachdev et al. (2014) also suggest that the term dementia should continue as it provides a commonality in public health, legislation and lay usage, arguing that on the whole it is widely accepted. In a bid to try and reduce stigma, reframing dementia by changing the word is something that may be worthy of further debate.

Although UK dementia policy aims to increase public awareness of dementia, to try to reduce stigma, it could be argued that it is also fuelling fears people may have about dementia. UK policy positions dementia as a national crisis and people with dementia as sufferers and a financial burden. Freud (1905) argued against what he termed the therapeutic nihilism of the over 50s, and perceptions that social and health resources are wasted on the elderly. Williamson’s (2012:4) report for the Joseph Rowntree Foundation: A Stronger Collective voice for People with Dementia, identified that much of this discourse is still evident, suggesting that decades of successive governments seem to have reinforced the rhetoric of dementia as a burden. This can be seen in policy narratives such as, The Rising Tide Government report (NHS Health Advisory Service 1982), which evoked images of dementia as a disease of epidemic proportions. This rhetoric of a disease epidemic is echoed again in 2012 with the Prime Minister’s Challenge (DH 2012), emphasising that dementia is feared more than any other illness among the over-55s.

The Prime Minister in his Dementia Challenge (DH 2012:3) invites the public to:

Imagine feeling confused and afraid because close friends and relatives feel like strangers; being unable to leave the house alone because you might not be able to find your way back; or seeing the fear in your loved one’s face, as they struggle to make sense of familiar surroundings.

Cottrell and Schulz (1993) contend that dementia is a social death, in terms of loss of social role and self-identity prior to biological death. The Alzheimer’s Society (2016) highlight a survey by YouGov which reported that two-thirds of people surveyed (62 per cent) stated that a diagnosis of dementia would mean their life was over. De Boer et al. (2007:1021), contends
that the fear the public holds about dementia are in fact fears of inadequate care and associated burdens rather than of the disease process. Bartlett (2000) asserts that older people with dementia face discrimination based upon negative stereotypes related to age as well as the social stigma associated with mental illness. Higgs (1997:197) conceptualises that old is primarily a social category, a position reinforced by Townsend (1981) who contends that it is produced by government retirement policy and wider social processes.

Alabaster (2007) found that nursing students identified that they felt that there was a stigma attached by nurses towards nurses caring for older people in wards specialising in caring for older people; which Page (1984:39) terms, stigma by association. Milne (2010:230), supports this suggesting that staff working in dementia care services are often under-valued in comparison to other areas of health and social care, often facing what she terms, secondary stigma. Cornwell (2012) also identified that working with older people is often viewed by nurses as a career lacking in status whilst Stevens (2003) found that there was a perception that caring for older people was viewed as second class work. Happell and Brooker (2001) and McCann, Clark and Lu (2010) highlighted that nursing older people was an area that many were reluctant to specialise in. The All-Party Parliamentary Group on Dementia: Prepared to care. Challenging the dementia skills gap (2009), recognised that this may be due to the low status and lack of career opportunities perceived within the health and social dementia workforce. Moreover, Thupayagale-Tshweneagae and Dithole (2007:145), alleged that the enemy of nursing is within the profession, arguing that nurses are guilty of victimising each other and not acknowledging the expertise of colleagues especially in caring for older people. This view is supported by Nay (2004:61) who proclaimed that:

If nursing is the poor cousin of health professionals, gerontic nursing has been seen as the untouchable illegitimate of nursing.

Arguably healthcare professionals contribute to the perpetuation of stigma through their behaviours (Craig et al. 2002), illustrated by older people and people with dementia being referred to as bed blockers, potentially reflecting ageist attitudes in society. Maben et al. (2012) used the term parcels to describe less favoured older patients in hospital in a study examining the links between staff experience of work and patient experience of care. They reported that older patients who staff felt were complex and perceived that they could not make a difference to, were often seen as difficult, resulting in dehumanising and less patient centred care.

Awareness of ageism and its impact was recognised with the introduction of age discrimination legislation in the Equality Act (2010) which provides protection against discrimination or
victimisation on grounds of age. The Equality Act also introduces a duty on public bodies, which includes nursing and HEIs, to eliminate discrimination, thereby encouraging them to consider how their services affect older people. Ageism contravenes the core values of professional nursing; adult nursing students are taught to provide person centred care that does not discriminate (Baillie and Gallagher 2010; McCormack, Dewing and McCane 2010; Manley, Hills and Marriott 2011; NMC 2015). Arguably HEIs could be accused of promoting stigma by failing to adequately include care of older people with dementia in their nurse curricula. Mandated dementia content is an opportunity to address how educators intend to ensure that the future nursing workforce are adequately prepared for practice to support people with dementia and their carers.

2.16 Role of Media in Perpetuating Stigma in Dementia

Popular media may be viewed as an important cultural site that creates as well as reflects the awareness of the public in relation to health issues. Media can be seen as a powerful tool that may influence perceptions, beliefs and attitudes. Sabat (2001), argues that language is a powerful tool which can often influence how people with dementia are viewed. Critics suggest that within the media and academic literature the use of negative language to describe dementia exacerbates stigmatizing views of dementia (Brooker 2004; Milne 2010; Swaffer 2015). Although Doyle et al. (2012) asserts that the media can create awareness and communicate information about health issues, Kirkman (2006) suggests that it can also portray negative images of dementia, perpetuating stereotypes and stigma. An example of this is the way people with dementia are often described by the media as sufferers (Swaffer 2015). Van Gorp and Vercruysse (2012) review of studies into the way that dementia is portrayed in the media highlighted that they tend to focus on the terminal stage of dementia, thus this can often become representative of the entire trajectory of dementia.

Although dementia has received more interest and attention as a result of the surge in governmental interest in prioritising dementia; its portrayal in the media remains problematic. Many argue that the negative imagery used by the media in their portrayal of dementia perpetuates ageing stereotypes and stigma of the condition thereby reinforcing the publics’ negative perceptions of the condition (Clark 2006; Kirkman 2006; Peel 2014; Zeilig 2014). Peel’s (2014:890) thematic analysis of 350 UK national newspaper articles identified that dementia has often been represented in catastrophic terms such as, tsunami, ticking time bomb and worse than death. Similarly Zeilig (2014:260), in an article examining dementia as a cultural metaphor, highlighted how dementia is often associated with imagery of flooding with
phrases such as, *rising tide of dementia, wave of dementia* and *silent tsunami*, frequently used. This imagery can be seen to further emphasise the risk to everyone and if viewed from the biblical point, as a threat to humanity. Similarities have been drawn between representations of dementia and the portrayal of HIV/AIDS in the 1980s in terms of their portrayal as natural disasters (Jolley and Benbow 2000; Zeilig 2014).

Whitehouse (2012:107) describes language as, a powerful and ever-evolving force for social change. As far back as 1997, Kitwood (1997:37) in his discourse analysis of person centred care highlighted a headline, *Alzheimer’s: No cure, no help, no hope*. Although dated, this appears to continue to reflect public perceptions of dementia, as more people over the age of 55 feared dementia than death (Alzheimer’s Research 2011). A more recent YouGov survey (Alzheimer’s Society 2016), highlighted that almost two-thirds of people (62 per cent) surveyed felt that a diagnosis of dementia would mean their life was over, reflecting the fear that many people have about dementia.

### 2.17 Students Perceptions of Caring for Older People with Dementia

Coghlan and Brannick (2010) aptly use the term *framing* to describe establishing the contextual nature of the research enquiry. Both Ford and McCormack (2000) and Happell and Brooker (2001), identified that nursing curriculum is an important factor which helps to contribute to the attitudes of nursing students towards older people and their intention or not to work with them. Beck (1996:996) reported that nursing students used terms such as: *afraid, frustrated, sad and nervous*, to describe their feelings towards caring for people with dementia. Davies et al. (2000) argues that attitudes of nurses towards older people and people with dementia is a reflection of society’s perceptions of ageing which will be explored later.

Most published studies appear to have focused on the attitude of nursing students’ to and experiences with older people; with few focused on people who are living with dementia. Findings suggest that there are many influencing factors that may contribute to nursing students’ attitudes towards older people. Robinson and Cubit (2005) identified that nursing students associated fear of ageing with distaste and discomfort with ageing bodies. This resonates with Beck’s (1996) earlier study highlighting the phenomenon of *ageing anxiety*, whereby students became anxious and frightened of their own ageing process. Beck reported that nursing students’ identified becoming *hardened*; expressing feelings that they became robots providing physical care, *tuning* out patients who were cognitively impaired (ibid). Henderson et al. (2008:34) also found that nursing students viewed *working with older people*
as boring and frustrating, lacking challenge and their perception was that they are waiting to
die. Stevens and Crouch (1998:10) study identified that nursing students placed more value
on tasks; regarding them as the real role of nursing; conversely caring was viewed as basic
nursing (Stevens and Couch 1998:15). These findings resonate with many studies which
identify that nursing students viewed older care environments as not enabling them to develop
the clinical skills that they felt they needed to develop to become qualified nurses working in
faster paced environments (Abbey et al. 2006; Evers et al. 2011; Swanlund and Kujath 2012).

Only a few studies focused specifically on exploring adult nursing students’ experiences of
caring for older people with dementia. Baillie, Cox and Merritt (2012b) identified that factors
such as inappropriate hospital care environments, poor skills and knowledge of practice staff
contributed to nursing students’ feeling insufficiently prepared. Skaalvik, Norman and
Henriksen (2010) reported that nursing students felt that nurses in practice appeared to be
insufficiently prepared to support people with dementia; suggesting that this impacted on their
confidence and learning in practice. Both Skaalvik, Norman and Henriksen (2010) and Davies
(2014), identified that nursing students reported that they did not routinely experience
approaches in practice that were person centred. Davies (2014:1150) suggested that this
contributed to third year nursing students’ in their study reporting, feeling insufficiently prepared
to support people with dementia when in practice.

Studies investigating the key components of quality patient experiences of care demonstrate
that technical skills are consistently ranked higher than compassionate qualities by
practitioners (Flocke et al. 2002; McDonagh et al. 2004). Xiao et al. (2012), also found that
nursing students considered personal care to be valueless in their learning. Beattie et al. (2014)
and Baillie et al. (2015) argue that this is a reflection of media images of nursing. They contend
that nurses are often depicted in the media working in fast-paced technology rich acute care,
as opposed to working with older people and people with dementia, which they argue can
create preconceptions amongst nursing students about the nature of nursing. As Celik et al.
(2010:25) contends:

Today’s students are tomorrow’s health care professionals, the development and
cultivation of positive attitudes towards ageing and older people is crucial.

2.18 Career Destination of Newly Qualified Nurses

Although caring for older people and older people with dementia, is a major part of the work of
the NHS, literature has consistently shown that there appears to be a culture amongst nursing
students as well as registered nurses, that does not seem to value working with older people very highly (Brown et al. 2008; McKinley and Cowan 2006; McKinley and Brown 2014; Wareing et al. 2017). Geriatric services have historically been viewed as Cinderella services, places where nurses perceived not to hack it in more acute services were banished, as there is a belief that older adult care is simple (Brown et al. 2008; Xiao et al. 2008). Moyle (2003) found that students’ reported that they felt aged care environments were depressing and their perception was that everyone was dying. Furthermore studies have also found that nursing students’ perceive that working in aged care required a minimal knowledge and skills; signifying the end point of one’ s nursing career (Abbey et al. 2006; Henderson et al. 2008). Nay (2004) suggested that working in older adult care is often perceived as an area for nurses whose care is deficient, she found that some new nurse graduates reported that they experienced pity for choosing to work with older adults. In a later study, Stevens (2011) study on career destination also identified that working with older people was not considered as prestigious as nursing in other clinical areas.

Steven and Crouch’s (1995) longitudinal study reported that nursing students viewed caring for older people as mundane and routine. In a replicated study involving over 500 nursing students, Happell (2002), found that working with older people was the least preferred area of practice and career choice, with only 1.9 per cent of students choosing geriatric nursing as their first choice. Happell (2002) identified that the most desirable areas of nursing practice involved technology that focused on curing illness and saving lives, rather than areas that nursing students’ perceived as adopting caring roles. This finding reflects Stevens and Crouch (1995) observations of what they term care-cure dichotomy; whereby they argue that nursing students are socialized in preferring a cure rather than care approach. Unfortunately a later study by Steven’s (2011), found little difference in nursing career preferences. His replicated career destination study involved 150 nursing students and correlated earlier studies of Steven and Crouch (1995) and Happell (2002) that working with older people remained the least preferred career choice.

Several studies suggest that academic year may influence nursing students’ attitudes towards people with dementia, with more senior students generally reporting more positive attitudes towards caring for people with dementia than first year students (Lambrinou et al. 2009; Skerri and Skerri 2013; Baillie et al. 2015). Henderson et al. (2008) study of first year nurses also found that working with older people was the least preferred career option for first year adult nursing students. Skerri and Skerri (2013) and Baillie et al. (2015) reported various contributing factors that could account for this such as, increased confidence in the third year as well as
pre-course contact. Stevens (2011) also identified a correlation between the number of days and career rankings, he found that the more days spent on practicum resulted in poorer rankings and the popularity of working with older people declined. He reported that only 3 of the 150 participants of the study stated a desire to work with older people at the end of their training. McCann et al. (2010), also identified that only 1 per cent of students in Year 1, 2 per cent in Year 2 and no students in Year 3 wanted a career in gerontological nursing. They identified that poor clinical placements, negative influences of the media, lack of curricula content and discouraging contact with student peers, new graduates and other registered nurses were all identified as influencing factors. A more recent study by McKenzie and Brown (2014) explored factors influencing intentions, as well as perceived barriers to working in dementia care of first, second and third-year undergraduate nursing students (n=135). Professional barriers identified included conditions and culture, personal demands both physical and emotional which were similar to Happell's (1999) earlier study.

Studies of medical and nursing students identified that students’ exhibited less caring behaviours and were less empathetic towards the end of their training (Hojat et al. 2009; McIntosh 2009; Murphy et al. 2009; Neumann et al. 2011). Practice placements comprise 50 per cent of curriculum hours in both UK and Europe, evidence demonstrates that they influence students’ perceptions of nursing (Brown et al. 2008; Eick, Williamson and Heath 2012; Baillie et al. 2015). Numerous studies suggest that practice placements help nursing students consolidate their vision of nursing and also to determine the type of speciality they choose to work when they qualify (Steven and Crouch 1995; Happell 1999; Happell 2002; Brown 2006; Stevens 2011). However, as Saltzer (1981) points out, behavioural intentions do not always reflect behavioural outcomes. Although numerous studies have explored intentions to work in aged and less so in dementia care settings; no longitudinal studies could be found that explored the intention and outcomes of first career destination amongst adult nursing students in relation to dementia. One of the key contributions of this longitudinal study, is that findings of career destination will add to the evidence of first career destination of adult nursing students.

2.19 Innovative Curriculum Activities

The World Alzheimer Report (2016) advocates the development of experiential methods of teaching involving contact with people with dementia to engage healthcare students in dementia care (Prince et al. 2016). As Baillie et al. (2015) asserts, adult student nurses must be adequately prepared during their training to ensure they have a realistic understanding that their roles will involve caring for older people living with dementia. Mandated dementia content
in healthcare curricula presents HEIs with challenges of how best to integrate mandated dementia education into their curricula in a meaningful way. Engagement with creative approaches, such as *Time for Dementia*, that involve nursing students listening to people with dementia and their carers; inviting them to walk in other people’s shoes and reflect on their own situations may help to engage nursing students and improve dementia care in the future.

2.20 Involving People with Dementia in Healthcare Education

UK policy makers clearly advocate that dementia education needs to be improved (DH 2009; Alzheimer’s Society 2010; DH 2013b; DH 2015). Deficiencies in the knowledge and skills of healthcare professionals caring for people with dementia were highlighted in *The National Dementia Strategy* (DH 2009a). Subsequent analysis of education and training by the Department of Health and Skills for Care (2010) highlighted lack of dementia education at early stages of healthcare training may be the most significant gap. To try and address this gap, *Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values* was published (DH 2013). This Government mandate to Health Education England (HEE) ensured that by September 2015, all undergraduate courses included dementia (DH 2013) to ensure newly qualified practitioners have the knowledge and skills to care for people with dementia. In a bid to respond to these professional and regulatory body and Governmental requirements HEIs need to ensure they balance *doing it versus doing it well*.

Although UK literature identifies that patient and carer involvement is increasingly important in healthcare education and practice (Baggot et al. 2005; NMC 2010), research related to the benefits of involvement in nurse education remains limited, with few longitudinal studies looking at impact beyond registration (Carr 2004; Tew et al. 2004). Studies of service user involvement in mental health nursing suggests that benefits of user involvement in education include, adopting a person centred approach which may lead to enhanced empathetic understanding of the experiences of service users (Wood and Wilson-Barnett 1999; Downe et al. 2007; Repper and Breeze 2007; Tee et al. 2007; Morgan and Jones 2009; Simpson et al. 2009; Stickley et al. 2009; Tew et al. 2011). There is also a growing body of evidence highlighting that direct contact with persons who are stigmatised can help to reduce stigma, by increasing understanding and challenge attitudes and beliefs (Morgan et al. 2002, Alexander and Link 2003; Couture and Penn 2003; Schreur, Lea and Goodbody 2015). Visiting people with dementia and their carers fits the education models of both pedagogy and service-learning. Dewey, as early as 1938, noted that education of social value could not take place in abstract
classrooms, advocating that the community should be involved in healthcare training. Subsequently Allport (1954) in his intergroup contact hypothesis, suggests that prolonged positive contact between different groups can help to reduce prejudice. This view is supported by Dorenlot (2005), who argued that people with dementia can help challenge negative constructions by speaking about their lives. Lamentably as identified in the literature review, research into service user involvement of people with dementia in education in comparison to other disability groups’ barely exists.

The active involvement of service users in education is articulated in many Government policies. The NMC standards for pre-registration education (NMC 2010; 2016), reflect the changing landscape of care and shift from hospital care to community nurse curricula needs to reflect this shift to understand the lived experiences of patients. Rosowsky (2005) and Angus and Reeve (2006) suggest that increased contact with older adults can help to foster an understanding of them as individuals, potentially helping combat ageism. The lived experience of dementia is unique and this experiential knowledge is often not something that health professional educators possess. It is acknowledged that, as in the case of the researcher, it may be something that they have lived experience of, through the role of being a family carer. Nurse Education must include the voice of people with dementia to enable students to learn with rather than about their lived experiences, thereby reinforcing that the inclusion of voice is one of the key capabilities for a socially inclusive society. Consequently innovative educational programs are more important than ever, as regardless of career destination of students’ when they qualify as life expectancy increases, skills in dementia care are essential. Engaging with hearing about the lived experiences of people with dementia and their carers offers adult nursing students a different discourse to the professional one that is traditionally shared by academics in education. Involving people with dementia in educational initiatives may enable nursing students to see beyond the clinical aspects of their role, encouraging them to include the essential human element of care.

Following recent reviews of nurse education in the UK, Raising the Bar (Willis 2015) and in Scotland, Setting the Direction for Nursing and Midwifery (2014), the NMC developed new pre-registration nursing standards which they will adopt from September 2019 (NMC 2016). The changes reflect the changing face of health and social care and supporting an ageing population and people with dementia. There has never been a more important time to prepare future nurses for an ageing population with increasing numbers of people living with dementia.
2.21 Summary

This Chapter presented the contextual background to the study. The context of people with dementia in society, healthcare and education as well as the theories of dementia was explored. The role of literature in constructivist grounded theory was discussed, followed by a scoping review of the involvement of service users with dementia in undergraduate adult nurse education. This defined the existing parameters and provided a frame for the research and identified existing knowledge and rationale for the research. Adult nursing students’ perceptions of working with older people and older people with dementia were also explored.

The next Chapter explores the choice of constructivist grounded theory methodology. Data collection methods and the process of data analysis are critically justified. The aims and objectives of the longitudinal nature of the research study are explored. Ethical issues related to this study and the measures taken to try to reduce the risk of harm to participants as well as the researcher are also outlined.
3 Chapter 3: Methodology

Every journey begins with a single step (Lao Tzu)

3.1 Introduction

The literature review demonstrated the lack of research in educational interventions involving adult nursing students and people with dementia and their carers, thus strengthening the impetus and rationale for the PhD study. The purpose of this Chapter is to describe the research design and methods adopted for this study. It commences with the research question and the aims and objectives of the study. Rationale is given for the constructivist grounded theory chosen for this study. In addition, a description of the main study’s research design, selection and recruitment of participants is provided. This Chapter also identifies the data collection methods and the analysis employed in the study and how literature as well as my observations from the research were used as a source of data.

An account of my biography, which provided a sense of my ontological perspective or worldview, was given in the introduction to this thesis in section 1.9. Choice of the research paradigm was influenced by my beliefs about the world and how it should be understood (Denzin and Lincoln 2005). Hence the qualitative approach enabled me to explore the research question and the perceptions of adult nursing students and the meanings they ascribed to their visits with people with dementia and their carers. This study was informed by the philosophical position of relationship and genuine dialogue; working with people with dementia as people rather than as objects (Buber 1970; Kitwood 1997).
3.2 Research Strategy and Design

The Research Question

What are student nurse perspectives on the impact of longitudinal home visits to people with dementia and their carers?

According to Glaser (1992) and Strauss and Corbin (1998), a broad research question can reduce the potential restriction of a narrow focus arguing that if a focus is too narrow it can limit understanding of relevant concepts.

3.3 Aims and Objectives:

The proposed study aims to add to the current evidence-base through addressing the following:

Aim:

The aim of this study was to explore adult nursing students’ perceptions of their experiences of visiting people with dementia and their carers over 3 years and the impact on their professional learning and practice.

Objectives:

1. To explore adult student nurses’ experiences of visiting people with dementia and their carers at home
2. To understand how contact with people with dementia and their carers impact on students’ understanding of dementia
3. To explore if and how regular contact impacts on care practice
4. To look at nursing students’ perceptions of the impact of the visits on their future career choices

3.4 Research Design

3.5 Longitudinal Nature of Study

Stories that can capture the essence of experiences over time which are truly authentic and invaluable in understanding the person for whom we care. (Welford 2007:33):
Both Morgan and Jones (2009) and Terry (2012) contend that the earlier the involvement of service users in nurse education, the more likely it is to have a lasting impact on their professional practice. As Dix (2014) suggests, there is a need for further longitudinal study to explore in order to support this assertion as there is a lack of longitudinal evidence, as exemplified in the literature review in Chapter 2. Parahoo (2014), suggests that one of the primary problems of longitudinal research is the risk of participant dropout during the study period due to disengagement. To try to reduce attrition of participants of the study, various methods were used; providing information to participants, follow up emails after each interview to provide a personal response and participants’ feedback about the study and being flexible when arranging interviews. Of the 12 participants who consented at the start of the project, 8 participated throughout all four phases of the study (Table 4 pg. 70).

In this study, experiences and perceptions of adult nursing students’ visits to a person with dementia and their carer were explored, where change over time (3 years) was extremely probable. Previous studies were limited, providing little information regarding the dynamic and changeable nature of adult nursing students’ experiences of the impact of service user involvement on their education and their impact on practice. Panel studies are longitudinal studies collecting information on the same participants at different points in time (Polit and Beck 2004), hence a panel study, which enabled examination of the phenomenon of the visits at a series of points in time whilst demonstrating the nature of the changes seemed most appropriate for this study. Design of this panel study involved three phases of interviews over three years involving the same adult nursing students’ visits during their three years of training and a fourth phase following up on first career destination (Figure 3, pg. 62). It was hoped that interviewing the same adult nursing students over three years may help to illuminate any changing perceptions, and explore any impact on the students’ professional learning and practice resulting from their visits to people with dementia and their carers.

The advantages of utilising a longitudinal element for this study meant that the study involved the same participants over time. As dementia is a progressive condition; the value of the longitudinal nature of visits is that they provide students with a unique opportunity to visit, as much as possible, the same person with dementia and their carer throughout the three years of nurse training. Participants’ visit information for both interview and focus group participants is summarised in Appendix 9.
Figure 3: Illustration of Longitudinal Phases of Study

Phase 1
Interviews
Year 1
n=11
Reflective Journals
n=7

Phase 2
Interviews
Year 2
n=9
1 Focus Group
n=5
Reflective Journals
n=6

Phase 3
Interviews
Year 3
n=8
Reflective Journals
n=4

Phase 4
Follow up career destination at 6 months (post qualification)
n=8

Steps taken after each interview / focus group to aid constant comparative analysis
3.5.1 Methodological Considerations: Quantitative and Qualitative Approaches

As Cresswell (2007) asserts, a research question can be addressed by a variety of methodologies, suggesting that knowledge of the nuances of each eventually gives the researcher confidence to make a choice. Both quantitative and qualitative methodologies were considered to respond to the research question, aims and objectives generated for this study. Historically, qualitative and quantitative approaches were viewed as opposing forces, which Silverman (2006) calls, the false dualism of research, as there is a danger that researchers draw contrasts and divisions between different approaches to qualitative and quantitative research. As Morse and Field (1996) acknowledge, there is a place for both qualitative and quantitative methodologies, however, Denzin and Lincoln (2011) argue that if little is known about the phenomenon it is better to choose a qualitative approach. As Marshall and Rossman (1999:15) claim:

Even if qualitative research produces more vague information, it is far better to have an approximate answer to the right question than an exact answer to the wrong question.

Sarantokos (2004:46) suggests that, if the researcher wants to know about what a person thinks and feels about an issue, this is suggestive of a qualitative study in an attempt to understand people, not measure them. Considering the lack of evidence of learning from service user and carer involvement in adult student nurse education, a qualitative approach was considered the most appropriate approach to address the research aims and objectives of this study.

As argued by Polit and Beck (2010) qualitative research is a methodology that is strongly focused on the understanding of human experiences as it is lived. As Clifford (1997) suggests it is a more holistic approach than quantitative research, which is why it is being used more frequently within the nursing profession (Streubert and Carpenter 2011). Qualitative research is based in the interpretive paradigm, rather than focusing on cause and effect, trying to deepen understanding of the phenomena. Hence its approaches tend to be more naturalistic and are used to explore, interpret or obtain an understanding of people’s personal experiences and perceptions. Parahoo (2014) suggests that the use of qualitative methodology to advance theoretical developments appears more appropriate when exploring under-researched areas. Although both quantitative and qualitative approaches have their strengths and weaknesses, and mixed methodologies can be informative, for the purpose of this study qualitative methodology was most suited to the enquiry.
3.6 Methodology

3.6.1 Rationale for Choice of Method

According to Blaikie (2000:8) methodology is the process of the \textit{critical analysis of methods of research}. There are many methods of qualitative data analysis including case studies, ethnography, grounded theory, oral biography and phenomenology (Flick 2009). As a novice researcher the process of exploring a range of qualitative methodologies has been valuable as there was a need to visit and understand the various options prior to making a decision of the most appropriate methodology for this study. My own beliefs and feelings influenced the choice of research paradigm and methods for the study just as they influenced the choice of research topic. The use of a qualitative approach was chosen as it enabled me to explore the experiences of adult nursing students and their perceptions following visits to people with dementia and their carers. As Holloway and Wheeler (2010) suggests, individuals are best placed to describe situations in their own words.

My ‘\textit{Aha}’ moment came after lots of reading, reflection and discussions with my supervisors of the different approaches to this research. Cutcliffe (2005), suggests that the grounded theory method has contributed significantly to nursing as an academic and research profession. As I explored grounded theory I chose this as the most suitable approach to answer the research question, to try and enrich my insight into the experienced reality of adult student nurses’ and the perceived impact of their visits, if any, on their learning and practice (Willig 2001). Strauss and Crobin (1998:11) suggests that:

\begin{quote}
\textit{The intricate details about phenomena such as feelings, though processes and emotions that are difficult to extract or learn about through conventional research methods are encouraged to emerge through grounded theory.}
\end{quote}

As Star (2007:77) emphasises, grounded theory can often produce:

\begin{quote}
\textit{The eureka of new; powerful explanations.}
\end{quote}

Grounded theory research methodology appeals to a range of disciplines due to it explanatory power (Glaser 2002). Classic grounded theory has its roots in symbolic interactionist sociology which emphasises how people relate to each other and seeks to construct theory about issues of importance in people’s lives (Charmaz 2003). Although over time there have been several permutations of grounded theory that have evolved (Lincoln and Guba 2000). McCann and Clark (2003) suggest that any form of grounded theory requires the researcher to address a set of common characteristics (theoretical sensitivity and sampling; treatment of the literature;
constant comparative methods; coding; identifying a core category, memoing and measuring rigor). Mills, Bonner and Francis (2006), contend that the form of grounded theory depends on the nature of the relationship between researcher(s) and participant(s).

Constructivist grounded theory can be traced from the work of Strauss (1987) and Strauss and Corbin (1998) and is underpinned by their relativist position. According to Glaser (2000), this is demonstrated in their belief that the researcher constructs theory as an outcome of their interpretations of patients’ stories. This approach differs from classic grounded theory as it re-shapes the interaction between research and participants as the researcher is positioner as co-producer to enrich the data (Charmaz 2003).

3.7 Technique Selected for this Study: Constructivist Ground Theory

Grounded theory was considered the most compatible methodology for exploring the perspectives of adult nursing students’ on their learning with people with dementia and their carers. Mills, Bonner and Francis (2006) suggests that because grounded theory seeks to discover issues important to the participants' lives it provides great potential for nursing research. In its traditional form of classic grounded theory, the reciprocal nature of the researchers’ relationship with their participants does not seem to be valued, however, this relationship is viewed as important and recognised by constructivist grounded theory (Charmaz and Mitchell 1996; Mills, Bonner and Francis 2006). Rather than referring to myself as the researcher, I will refer to myself using the first person to include my own voice in the writing; thereby acknowledging the shared experience of the process. As Charmaz (2008: 133) argues:

*Entering the phenomenon shrinks the distance between the viewer and the viewed. Subsequently, we might better understand our research participants multiple realities and standpoints.*

According to Mills, Bonner and Francis. (2006), grounded theorists take on an epistemological position of subjectivism, as it acknowledges underlying assumptions with respect to the area being studied. As a researcher, clinician and lecturer; I am part of the world that I am studying. As a co-constructivist it was important for me to include my own voice in the study, as the area is of interest to me I did not want to be merely a data gatherer. As Smyth and Holian (2008:40) advocate:

*Pre-understanding... enables a deeper and more insightful investigation and exploration of the issue and especially the most unspoken aspects that may elude an outsider.*
The role of the researcher is acknowledged as an active passionate participant (Lincoln and Guba 2000:166) utilising the voices of all participants to ensure co-construction of a theory of the social phenomena. Results are therefore shaped by both the researcher and participants which was a really important approach for me to emphasise throughout the study. The decision to use grounded theory was just a starting point as the challenge was deciding which version was most suitable for me to use for this study as the grounded theory method has evolved since Glaser and Strauss (1967) original writings. After reviewing relevant literature, a constructivist grounded theory approach, as developed by Kathy Charmaz, was chosen over Classic or Straussian.

A constructivist grounded theory approach was chosen primarily because it places emphasis on making the researcher visible. Charmaz (2006) criticises grounded theory for its ‘distant’ relationship with participants, participants’ words and actions are viewed as a source of data and little attention is given to the researcher’s relationships with participants (Glaser 1978; Strauss and Corbin, 1990). Collins (1998: paragraph 1.1) aptly describes this approach as smash and grab to describe how participants are relieved of useful data. The ideas of Strauss and Corbin evolved to become more constructivist in their approach, as they later acknowledged that co-construction takes place between the researcher and participants during interviews which they term reciprocal shaping (Strauss and Corbin 1994:280). Moreover Strauss and Corbin (1998:11) contend that the intricate details about phenomena such as feelings and emotions that are difficult to extract or learn about through more conventional research methods are encouraged to emerge, encouraging a richer student nurse response.

Charmaz (2000) contends that methodologically, constructivist grounded theory is interpretivist in nature, as it is the researcher who interprets the reality arising from interactive processes of the study. It is assumed that reality, society and self are in fact socially constructed rather than objective reality in that we develop shared understandings in order to make sense of the world through social interaction with others (Gardner et al. 2010). This approach helped to facilitate the researcher’s understanding of how meaning is developed by the participants through their social interactions of visits to people with dementia and their carers.

It was also important to consider the theoretical principles that guide my profession of both nursing and education. The constructivist worldview is common in both education and nursing as it is essential to understand the subjective experiences of patients and students. Constructivist grounded theory has been applied by many researchers in both health and education to help them to understand experiences, behaviours and processes to inform
education and improve patient care (Mills, Bonner and Francis. 2008; Morberg et al. 2009; Duggleby et al. 2010; Gardner 2010; Byrne et al. 2011; Banner et al. 2012; Keane 2014). The use of constructivist grounded theory offers significant opportunities for researchers to evolve theoretical perspectives that can guide and inform practice. Critics of constructivist grounded theory contend that reliance on secondary sources can expose the method of grounded theory to potential bias (Bryant and Charmaz 2007). Furthermore Glaser (2002), criticises this approach of co-construction of understandings between the researcher and participants, viewing the interviewer as an unwanted intrusion in the process.

Constructivists reject the post positivist stance of the observer as neutral, as espoused by Glaser (Charmaz 2007; Gardner et al. 2010). Charmaz (2006:184) contends that this approach fosters openness and empathetic understanding of participants’ meanings, actions and worlds which can potentially transform practice. For these reasons constructivist grounded theory was chosen as the most suitable ontology for this research as it seeks to understand the perceptions of adult nursing students of their visits with people with dementia and their carers in a non-clinical setting. As Charmaz (2006:130) expounds:

The constructivist approach means learning how, when and to what extend the studies experience is embedded in larger and often, hidden positions, networks, situations and relationships.

Strauss and Corbin (1998:11) goes further, suggesting that:

The intricate details about phenomena such as feelings, thought processes and emotions that are difficult to extract or learn about through more conventional research methods are encouraged to emerge.

All of the participants were new to the experience of being a student nurse hence the constructivist grounded theory method allowed them to develop, build and share perceptions of their visits as they progressed over the three years.

3.8 Participants: Selection, Sampling and Recruitment

Charmaz (2006), Stern (2007) and Morse (2010) suggest that as the process of grounded theory is emergent, the number of participants is not known at the start. Consequently there appear to be no firm guidelines for sample size in grounded theory research; and according to Sandelowski (2001), it is often a matter of judgement that is based on the study and resources. Charmaz (2006) suggests approximately 25 interviews is sufficient for a medium sized study, supported by Stern (2007) who advocates that 20-30 hours of observations are often enough to reach saturation. However, to ensure that I met relevant university ethical requirements, I
needed to include an estimate of the number of participants for the study in my research proposal. As a novice to grounded theory I based my estimate of the number of participants \( n=15 \) on the available literature; as this number was in keeping with other studies from this tradition. Discussion of theoretical sufficiency or saturation will be analysed later in this Chapter.

Purposive sampling was used to recruit participants in accordance with a grounded theory approach (Denzin and Lincoln 2005). As Glaser (1998, 2003); Morse (2010 and Streubert and Carpenter (2011) suggest, the goal of grounded theory is to understand the actions undertaken in a specific substantive area from the point of view of the people involved. In this case the people involved were adult nursing students in the September 2014 cohort \( n=120 \). This was the first cohort of adult nursing students to participate in the *Time for Dementia* programme, students were allocated time in their curriculum to visit a person with dementia and their carers every 3-4 months throughout their three years of training. Visits occurred during their clinical practice placements (approximately 3-4 visits per year). The inclusion criteria is summarised in Table 3. As Morse (2010) suggests; researchers employing a grounded theory approach: *need to locate excellent participants to obtain excellent data*.

**Table 3: Inclusion Criteria for Participants**

| First year nursing students (September 2014) involved in *Time for Dementia* programme visits |
| Studying for BSc Adult nursing in Higher Education |
| Those students who agree to participate providing informed consent |

In light of my position as a teaching fellow within the same faculty and university as the adult nursing students to be interviewed, it was essential to address ethical concerns of engagement of participants' to the study. These concerns are addressed in Chapter 3. The administrator for the larger *Time for Dementia* programme was involved in supporting recruitment by emailing potential participants (Appendix 3). This approach was taken to reduce the *effects of faculty power in the relationship* (Ferguson et al. 2006:707), as the administrator was not a member of the teaching faculty. Due to the dynamic nature of the research process it was difficult to decide on the sample size at the start of the research, what follows is the description and justification of the process. A summary of participants is included in Table 4 (pg. 70).
### Table 4 Participant Profiles (Interviews: Phases 1-4)

<table>
<thead>
<tr>
<th>Participant Ref number*</th>
<th>Age of participant (years)</th>
<th>Gender</th>
<th>Prior dementia experience (Personal or professional)</th>
<th>Phase 1 Date of interview</th>
<th>Phase 2 Date of interview</th>
<th>Phase 3 Date of interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>31</td>
<td>F</td>
<td>No</td>
<td>19.11.15</td>
<td>19.09.16</td>
<td>15.05.17</td>
</tr>
<tr>
<td>2</td>
<td>30</td>
<td>F</td>
<td>yes worked in a dementia care home</td>
<td>23.11.15</td>
<td>19.09.16</td>
<td>24.05.17</td>
</tr>
<tr>
<td>3</td>
<td>23</td>
<td>F</td>
<td>‘bit’ volunteered 1 day a week in dementia residential home</td>
<td>11.01.16</td>
<td>Withdraw from study</td>
<td>Withdraw From study</td>
</tr>
<tr>
<td>4</td>
<td>18</td>
<td>F</td>
<td>Some work experience - mainly alcohol related dementia</td>
<td>07.01.16</td>
<td>12.10.16</td>
<td>19.05.17</td>
</tr>
<tr>
<td>5</td>
<td>25</td>
<td>F</td>
<td>No</td>
<td>13.01.16</td>
<td>02.11.16</td>
<td>29.06.17</td>
</tr>
<tr>
<td>6</td>
<td>18</td>
<td>F</td>
<td>‘Bit’-work with people with learning disabilities, some had dementia</td>
<td>16.01.16</td>
<td>19.10.16</td>
<td>Telephone interview 11/07/17</td>
</tr>
<tr>
<td>7</td>
<td>21</td>
<td>F</td>
<td>Minimal worked in independent assisted living home</td>
<td>14.01.16</td>
<td>05.10.16</td>
<td>Withdraw From study</td>
</tr>
<tr>
<td>8</td>
<td>38</td>
<td>F**</td>
<td>No</td>
<td>14.01.16</td>
<td>05.10.16</td>
<td>16.05.17</td>
</tr>
<tr>
<td>9</td>
<td>19</td>
<td>F**</td>
<td>Personal - grandparent</td>
<td>19.01.16</td>
<td>Withdraw from study</td>
<td>Withdraw from study</td>
</tr>
<tr>
<td>10</td>
<td>49</td>
<td>F</td>
<td>No</td>
<td>21.01.16</td>
<td>Course interrupt</td>
<td>Course interrupt</td>
</tr>
<tr>
<td>11</td>
<td>24</td>
<td>M**</td>
<td>No</td>
<td>10.02.16</td>
<td>4.10.16</td>
<td>19.05.17</td>
</tr>
<tr>
<td>12</td>
<td>29</td>
<td>M**</td>
<td>Personal - grandparent</td>
<td>Delayed visits – family withdrew</td>
<td>10.08.16</td>
<td>16.05.17</td>
</tr>
</tbody>
</table>

**Key:**
- *Assigned to participants to assure anonymity
- **Indicates participants from non-white background**

## 3.9 Choices of Data Generation

Research methods are an essential part of any project as they determine its success, validity and reliability. Due to the fundamental epistemological differences underpinning qualitative and quantitative methodologies the methods of data collection used differs. Using grounded theory enabled a more flexible approach to data collection that enabled emergent data to help guide future data collection strategies in accordance with the direction that the data takes (Charmaz 2006). Although Charmaz (2006:15) suggests that methods are merely tools, she suggests that the researcher still needs to consider their appropriateness in trying to answer the research question posed arguing that how data is collected impacts on the phenomena the researcher sees.
A variety of methods are used in qualitative research to collect data, however, in healthcare research particularly grounded theory, the most common methods used are interviews and focus groups, therefore both approaches were considered for this study. Initially, interviews were chosen as the most suitable data collection method to address the focus of the study and make audible the individual perceptions of adult nursing students of their experiences. Although the use of focus groups was considered for their potential in obtaining a number of viewpoints, their use was initially rejected due to concerns that emerging views would be those of the most dominant members of the group (Bryman 2008). As the study progressed in phase 2 the study did also, in the end, make use of data generated by a focus group. I decided to incorporate a focus group as it was important to choose a variety of data collection methods that yielded rich data. In all 3 phases of the project, interviews were used to generate data to begin to develop an in-depth understanding and are frequently used to generate data in grounded theory studies (Charmaz 2006; Mills, Bonner and Francis. 2006; Corbin and Strauss 2009).

3.9.1 Research Interviews

To provide an understanding of the social phenomena and to explore the perceptions of the experiences of participants’ interviews were used as more detailed insights were required from the participants. Used in conjunction with the focus group, individual interviews enabled me to fully explore participants’ individual responses and the meanings they derived from their interactions with people with dementia and their carers in order to develop theoretical findings. As Charmaz (2006:28) advocates, interviewing enables the researcher more control over construction of the data. Furthermore, the use of interviews gave me both control and flexibility to probe the students’ perceptions of their visits. As Bowling (2009:407) suggests, the use of in-depth interviews for grounded theory data collection enables the researcher to:

Delve deep beneath the surface of superficial responses to obtain true meanings individuals assign to events and the complexities of their attitudes, behaviours and experiences.

According to Parahoo (2014) there are three fundamental types of research interviews; structured, semi-structured or unstructured interview. Structured interviews ask all participants the same questions in the same manner and order (Holloway and Wheeler 2010). As structured interviews can often only allow limited participant response and do not allow for further exploration, they were not considered suitable for this study. Although Balls (2009) argues unstructured interviews are the gold standard for qualitative research, Patton (2003) argues
that they are difficult to manage and there is no such thing as an unstructured interview. Duffy et al. (2004), asserts that the philosophical assumption of grounded theory implies reliance on semi-structured as opposed to structured interviews. As both Duffy et al. (2004) and Parahoo (2006) suggest, semi-structured interviews can encourage participants to talk more freely about topics, affording the flexibility to follow-up responses for further elaboration and were therefore chosen as an appropriate approach to this study (Appendix 11).

Ezzy (2010) suggests that qualitative researchers mainly focus on the cognitively articulated aspect of interviews arguing that reflection on the emotional framing is important in interviewing. He argued that this enables the researcher to listen more openly to their participants and uses the analogy that in doing so they frame interviews more like a *communion than a conquest* (Ezzy 2010:168). Supported by Mason (1996:36) who suggests that to emphasise the interactive nature of interviewing the term *data generation* is a more appropriate term to use instead of data collection, and best reflects my approach to interviewing.

3.9.2 Constructivist Interviewing

A constructivist approach to interviews was taken to try and ensure participants remained at the centre of the process and to enable exploration of the perceived psychosocial impact of the visits, if any, on participants the interviews were repeated on an annual basis. Interviews provided opportunity for the narrative accounts of the experiences of participants to be captured. Consistent with Charmaz's (2006) constructivist approach the participant was at the centre of the constructivist interviewing and data was collected through semi-structured interviews with each participant. Through the interviewer's use of self; building relationships with participants and being sensitive to the research question quality data is constructed in the interview (Charmaz 2006).

Longitudinal interviews were chosen in an attempt to aid the researcher in trying to capture the evolving experiences and perceptions of the participants over their three years of visits. As Gillham (2000) suggests, as a novice researcher an interview prompt was developed and used to remain open and responsive to the responses of the participants during the interviews (Appendix 11). The initial interview prompt was constructed following the preliminary literature review and was also informed by the research problem. Prompts were intentionally made quite general and open to try to avoid the imposition of any preconceived notions upon the students’ perceptions of their experiences. As Morgan (1995) argues the emphasis is on participants’ perceptions of their experiences rather than the researcher’s perceptions of the issues being
investigated. My role within the interviews was to try to facilitate the students’ articulation of experiences of their visits to people with dementia and their carers. Open-ended prompts such as *Tell me about your experiences of your visits as part of the Time for Dementia project,* encouraged participants to share their experiences and story. As advocated by Charmaz (2006), sensitivity to participants was used throughout the interview to just listen or ask questions which allowed participants to main control and tell me about their experiences. The purpose of the interviews was to enable participants to reflect and share perceptions of their visits. All interviews were face to face except for one telephone interview. During phase 3 it was agreed to conduct a telephone interview with participant 6 due to her clinical placement commitments.

Interviews were considered the most suitable approach for this study because of the focus on personal experiences and perceptions as well as offering the space for lengthier narrative expressions by the students (Hernandez et al. 2010). In-depth interviews were used in phases 1, 2 and 3 of the study to generate rich and detailed accounts of individual experiences, however the lens changed in phase 2 to incorporate a focus group. A modification in data collection was made to include a focus group in phase 2 involving different participants (*n*=5) to the participants interviewed over the 3 phases of the study. This strengthened the claim to adequately represent participants’ perceptions of their experiences of visits. This approach is supported by Charmaz (2006:14) who expounds the use of a number of different data collection methods to try and discover theory:

> Like a camera with many lenses, first you view a broad sweep of the landscape. Subsequently, you change your lens several times to bring scenes closer and closer to you.

Although Munhall (2003) uses the analogy of a jigsaw in relation to observations in qualitative research, I considered that although interviews made up most of my research jigsaw, focus groups complemented this approach and enabled construction of the overall research jigsaw. Using semi-structured interviews and focus groups is consistent with grounded theory methodology to confirm findings (Duffy et al. 2004; Plack 2006). Halcomb and Andrew (2005) supports this approach, suggesting it adds to data completeness as well as confirmation of findings.

3.10 **Focus Groups**

According to Duggleby (2005), the primary goal of focus groups is to use the interaction data that results from participant discussions; through commenting on each other’s’ experiences
and questioning each other; to increase the depth of inquiry. Kamberelis and Dimitriadis (2005:903) suggest that focus groups takes the interpretive process: beyond the bounds of individual memory, mining collective memories. Although Parahoo (2014) acknowledges the criticism that data collected in focus groups is group opinion rather than individual thoughts and feelings, he argues that they can be useful in generating information on collective rather than individual views and meanings. This point is supported by Bohnsack (2004), who argues that the group effect is not necessarily problematic. He suggests that group opinion is especially valuable for evaluation purposes arguing that, conversational interactions can often stimulate deep or latent opinions (Bohnsack 2004:214). Moreover Flick (2009) contends that focus groups provide more natural everyday types of interactions than individual interviews, particularly in obtaining opinions about shared mutual experiences. Kidd and Parshall (2000) echo this view, suggesting that individuals do not answer questions in the same way as in individual interviews. Twinn (1998) suggests that focus groups could reduce the pressures on participants as they do not need to respond to all the questions. Although Holloway and Wheeler (2010) contend that findings from focus groups tend to lack generalizability, Ellis (2013) advocates that focus groups can help to encourage participant discussions and explore their thoughts on a topic. Furthermore Parahoo (2014) contends that participants may feel more comfortable discussing their perceptions in a group which could provide significant data and insight into complex research topics involving motivations, values and behaviours. Additionally Wilkinson (2004), supports this stance arguing that focus groups are more naturalistic as they follow everyday conversations within a group, thus generating rich data as members discuss and debate through their interactions. Loiselle et al. (2007), argues that this may provide the researcher with different views about the same phenomenon, contributing to credibility and expanding breadth and depth of findings.

Review of the literature indicated that focus groups should ideally consist of between 4-12 participants (Jameson and Mosel Williams 2003; Kreuger and Casey 2005). The focus group in this study consisted of 5 different participants to the main study participants (Table 5, pg.75), Jameson Mosel Williams (2003) supports a smaller number of participants, arguing that too many participants may limit optimal participation of all the members of the group. It was essential that participants felt comfortable to discuss their experiences of visits so to create a relaxed atmosphere interviews and the focus group were conducted at a time to suit participants. The focus group was held at a university, a naturalistic setting that was a familiar place where the adult nursing students were studying (Cresswell 2007). A guide was developed with prompts from phase 1 to help guide the researcher and elicit participants’
perceptions of their experiences (Appendix 12). At the start of the focus group interview I explained the purpose and established ground rules in relation to consent (Appendix 5), communication and confidentiality. Recording was undertaken using digital recorders, consent for recorded interviews had been sought prior to the focus group interview and again at the start of each interview and focus group. Memos were also written after each interview to note information such as non-verbal communication; thoughts and feelings and reflections on what was learned from that interview as well as impressions about the experiences of participants. An extract of one of these memos can be found in Appendix 18.

The introduction of a focus group alongside interviews in phase 2 enabled perspectives from different participants to share their perceptions and experiences of visits. A summary of participant profiles of the focus group is included in Table 5. This approach is supported by Lambert and Loiselle (2008) who suggests that combining interviews and focus groups enhances trustworthiness of findings as parallel use adds to data completeness and/or confirmation. The interaction data resulting from the discussions amongst the participants accentuated and confirmed the similarities of findings from the individual interviews. As Strauss and Corbin (1998) suggested, combining focus group data with individual interviews contributed to the understanding of the structure of the phenomenon.

Table 5: Participant Profiles (Focus Group: Phase 2)

<table>
<thead>
<tr>
<th>Participant Ref number*</th>
<th>Age of participant (years)</th>
<th>Gender</th>
<th>Prior dementia experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>48</td>
<td>F</td>
<td>No</td>
</tr>
<tr>
<td>14</td>
<td>23</td>
<td>F</td>
<td>Personal – partner’s grandparent</td>
</tr>
<tr>
<td>15</td>
<td>30</td>
<td>F</td>
<td>Some – worked few bank shifts in a care home</td>
</tr>
<tr>
<td>16</td>
<td>49</td>
<td>F</td>
<td>‘Limited’ – personal grandparents</td>
</tr>
<tr>
<td>17</td>
<td>23</td>
<td>F</td>
<td>No</td>
</tr>
</tbody>
</table>

Key: *Assigned to participants to assure anonymity

3.11 The Development of Serial Interview Guides

The use of semi structured interviews in a grounded theory method enabled statements made by participants to be further clarified by me in the course of the interview. After the data was generated and emergent theory developed, the open-ended prompts were further developed and the interview guide revised based on the participants ‘responses (Appendix 11).
Returning several times to participants for further information through follow up interviews at phase 2 and 3 is congruent with a constructivist approach (Bryman 2008; Silverman 2010). It also provided opportunities and time for the participants to discuss their experiences whilst also addressing questions in previous interviews to aid continuing interpretation by the researcher. Although some people argue that it is debatable whether prior knowledge of the research setting is advantageous to the researcher (Suddaby 2006; McGhee et al. 2007), I found that having prior knowledge about dementia nursing enabled me to ask specific prompts related to their visits. As potential categories began emerging from coding interviews, areas to explore emerged and as the data collection progressed, in order to develop the conceptual ideas and depth within the emerging categories, I acknowledged that I needed to try to introduce conceptual questioning without forcing the data. Exploration of the grounded theory literature highlighted there may be tension trying to balance questioning without forcing the data (Charmaz 2006; Birks and Mills 2011). Gubrium and Holstein (2001), suggest that purposeful questioning can support and enhance the depth of data collection. Charmaz (2008) proposes, that if a conceptual phrase is used in questioning that does not resonate with participants they would not engage with the discussion. Indeed this was reflected during interviews whereby if a question did not mean anything to a participant they did not engage and talk about it. This was reflected in questioning about terminating visits at the end of the study. As previously discussed termination of visits emerged as a line of enquiry in phase 1 of the interviews, consequently I included more focused prompts in phase 2 interviews (Appendix 11) and focus group (Appendix 12):

Some students have mentioned ending their relationships at the end of the study - any thoughts about this?

I would question participants if they engaged with the prompts, however, if it was clear that they had not considered it and did not talk about it, this line of enquiry was not pursued.

Prompts were revised at each phase of the study, enabling the researcher to explore the conceptual ideas within the emerging categories, enabling participants to talk about what was important to them about their experiences (Charmaz 2000). In keeping with the constant comparative method of grounded theory, re-reading transcripts and memos throughout the collection of data enabled me to develop focused open-ended questions to help explore and define emerging categories. An example of a focused question developed to help explore the emerging ideas in phase 1 about concerns regarding ending relationships: Have you considered the issue of ending the relationship at the end of the visits, what are your feelings about this? As Charmaz (2006) suggests, a key factor in the development of concepts is
constant comparison of data whilst also ensuring that the voice of participants is preserved. I reflected that as I became more familiar with the participants’ and interested in how their stories developed over time it helped the dynamics of the interview conversations.

3.12 Reflexivity of Interview Process

I was known to all of the participants as a member of the faculty with an interest in dementia, so it was important to address the issue of being a member of teaching faculty and the potential impact this may have on the interviews, I was mindful of issues of coercion as my role could shape what the participants said. Ferguson et al. (2006:709) suggests that some participants may be reluctant to express negative opinions directly, arguing that they may say what they believe the faculty want to hear. In order to address this issue and try to reduce this potential it was important for me to reinforce to participants that I wanted to hear their perspectives of their experiences of the visits. I made it clear that my role as a researcher during the interview was to listen, ask relevant questions and to reflect back on the information they gave and is further explored in section 3.22.

Interviews were carried out between November 2015 and July 2017, lasting approximately 45-60 minutes. With the consent of participants, all interviews were audio-recorded and transcribed verbatim. Before starting each interview participant information sheets were given out again and discussed and questions about the study invited. According to Keats (2000), the closing of the interview is as equally important and at the end of each interview participants were all asked if there was anything they would like to add. This enabled participants to discuss anything they felt was important and had not been dealt with by the interviewer, which Kyale (1996) argues can potentially can lead to new, unanticipated information. Although many of the participants’ stated that they did not have anything else to add before the recording was terminated, I found that they often continued to talk providing really useful insights of their experiences, after the recording was stopped. These insights were recorded in the memos written after each interview, verbal consent to include was gained to include in the data. An example of this was captured in a memo (Appendix 18). Participants continuing to provide meaningful data following the end of interviews was also highlighted by Morse and Field (1996:68); they found that, data collection does not stop when the tape recorder is turned off. Finally each participant was thanked for their participation.

As suggested by Charmaz (2006), techniques such as paraphrasing and reflection were used in the interviews to enable data to be generated in a co-constructivist manner. At the beginning
of the process I was conscious that I did not appear to dominate the interview by asking too many questions. This was particularly important as a member of the faculty. As my confidence increased in the interview process prompts were utilised more to support participants in providing their accounts of their experiences. As the research progressed I checked understanding with participants more by reflecting back and checking my understanding with them. This also enabled even further explanations to be explored especially as codes were beginning to emerge. As data and analysis was concurrent, it enabled me to make changes to my approach and review the interview prompt questions to explore emergent core categories and related variables that emerged.

Although I considered that I had a lot of experience interviewing as an experienced senior registered nurse in clinical practice and my role in education, these interview situations were very different as I was usually in the role of practitioner or teacher seeking out specific information. Barbour and Featherstone (2000) points out that even if, as in my case, the researcher is accustomed to patient interactions and interviews, qualitative interviewing is different. As previously mentioned all the interviews were face-face except for one final phase 3 interview with participant 6. Due to the participant’s work commitments this was done as a telephone interview, which Birks and Mills (2011) assert is a valid reason in grounded theory study. Gillham (2005) argues that although cost effective, traditionalists regard telephone interviews as inferior. Reservations identified include the researcher being unable to create and maintain a rapport, lack of visual access to the interviewee and potential communications being confused or misunderstood (Gilham 2005; Rubin and Rubin 2006; Rowley 2012). However, as I had previously interviewed the participant on two occasions face to face I felt that we had built up a rapport and the conversation was free flowing. We engaged in small talk prior to recording the interview, I asked about their current placement and we talked about areas of interest in relation to applying for jobs. Sweet (2002), suggests that the level of rapport the researcher can achieve affects the quantity and quality of data extracted. In a study comparing 56 face-to-face interviews against the same number of telephone, Vogle (2013) found no significant differences in duration, number of words spoken, pauses or need for clarification. Gilham (2005) and Rowley (2012) suggests that visual clues, such as facial expression and body language are integral to the communication process, however, as highlighted by Qu and Dumay (2011), I reflected that I listened much more carefully in order to concentrate and direct the flow of conversation using appropriate prompts. Listening to the recorded interview, I found that I used ‘umms’ and ‘okay’ much more frequently in the telephone interview, which both Irvine et al. (2012) and Holt (2012) term as:
Communicating presence and understanding to what the interviewee is saying.

Although Glaser (2003) was critical of recording data; arguing that interviewers would remember all important information, as a novice researcher recording the interviews enabled me concentrate on what participants’ were saying instead of trying to take notes at the same time. Hammersley (2010) suggests that recording data preserves what is said, arguing that this enables analysis of the data to be checked and strengthening rigour to collection of data. As recommended by Charmaz (2006), audio recordings were transcribed verbatim by the researcher for detailed analysis to help reduce bias as it provides a permanent record of what has been said by participants. Audio recordings of each interview were transcribed as much as possible after each interview; as the process of grounded theory requires data collection and coding to explore emergent themes in subsequent interviews. An issue arose around scheduling of interviews in phase 1 (Year 1). To accommodate some of the participants; I had to undertake several interviews (n=5) within a short space of time (3 days). Consequently I had little time to transcribe data between the interviews to enable me to compare the incoming data with previous analysis. Although I kept notes in the form of memos, I reflected that I worked much better when I had time between each interview to analyse data as this enabled me to plan for later interviews.

Each interview was transcribed verbatim, which ensured that the supervisory team could check developing analysis whilst also checking for any potential bias. The process of transcribing was really useful in helping to develop my research skills, as I found that listening to the interviews helped to increase my understanding and also my conceptual thinking. Throughout each stage of the study, my learning was enhanced through critical colleagueship of both doctoral supervisors as well as with my peers. As a novice researcher I reflected that I found the process of transcribing the interviews really valuable as I identified that during the interviews I was not always aware of what was important. Taping the interviews enabled me to replay them throughout my analysis of the data, enabling me to go back and forth between the data during data analysis.

3.12.1 Reflective Journals

Thorpe (2002:328) defines reflective journals as:

*Written documents that students create as they think about various concepts, events, or interactions over a period of time for the purposes of gaining insights into self-awareness and learning.*
Reflective journals were used alongside interviews to help explore and capture the perceptions of students regarding their visits with people with dementia and their carers. Students were assured that their diary entries would remain anonymous. Langley and Brown (2010), suggests that reflective journals have the potential to support both the personal and professional development of self; however, there is a lack of evaluative studies on the benefits of using reflective journals in nurse education and much of the evidence is anecdotal.

I debated whether to use a structured or a semi-structured format for the diary entries. Gibson (1995) suggests that structured approaches could potentially influence the focus and may reduce spontaneity of participant entries. Consequently a semi-structured approach format was utilised, as advocated by Clayton and Thorne (2000), in a bid to try and address the balance of the researcher to meet the project objectives whilst trying to avoid too many preconceptions (Appendix 14).

It was anticipated that the analysis of reflective journals may help in the exploration of the student’s experiences and perceptions as in my experience, their use can often encourage the expression of feelings. Journaling may also encourage students to practice what Schon (1987) calls reflection in action, by recording their impressions and experiences about their visits. It was hoped that by maintaining a written record using their journal, that participants would be encouraged to reflect on their experiences, and identify any learning more explicitly to enable generation of richer data collection.

3.13 Sources of Data

Numerous methods were used to collect data during this study including face-to-face interviews, focus group, reflective journals, memos and consistent with the grounded theory approach; literature was also recognised as a source of data (Charmaz 2006). Each data source contributed to a deeper understanding of the students’ perceptions and experiences of their visits with people with dementia and their carers.

Literature and relevant policies were also utilised as a further source of data throughout. As previously explored, although the use of literature in grounded theory is contested, relevant literature will be interwoven into findings; seen by the researcher as another voice contributing to the findings of the study. Strauss and Corbin (1998), suggests that literature can provide examples of processes that are similar, asserting that this can stimulate thinking about the properties that the researcher can use to examine data. According to Charmaz (2006), literature can help the researcher to clarify their ideas, make comparisons and demonstrate
how and where the study fits or extends relevant literature. This approach helps to ensure results are positioned in the current dialogue within the discipline of adult nursing, and speciality of dementia in particular; it positions the study within the current knowledge of dementia education. Interviews were carried out over the duration of 3 years with follow up career destination at 6 months post qualification; Figure 3 (pg. 62) illustrates each phase of the data collection methods utilised for this study.

3.14 Phases of Data Collection

As previously discussed the study was planned over four phases. Phases 1-3 were conducted over a three year period with data collected over approximately twelve-month intervals, strengthening the longitudinal nature of the study. These intervals were based on the nature of the project as visits were carried out over three years of the adult nursing students training. Phase 4 involved a six month career destination follow up with the participants using email to confirm their first career destination (Figure 3, pg. 62).

3.15 Data Analysis

As Charmaz (2006) asserts, grounded theory is not a linear process, collection of data, analysis of data and development of theories occur simultaneously and theorising began as the data was analysed and emergent theories developed data collection was further developed. Strauss and Corbin (1998) suggest that data analysis is reliant on the researcher to interpret meaning and interconnections in the data in order to develop theory. As previously discussed interviews and the focus group were transcribed verbatim as soon as possible after completion. Memo writing was used, as proposed by Charmaz (2006), to encourage me to analyse data and codes throughout the process of the research. According to Charmaz (2006), memo writing in constructed grounded theory is both a data collection and data analysis method.

Both Glaser (2003) and Holton (2007) dismiss the use of software analysis tools for grounded theory studies, arguing that computers are unable to replace human thinking. Although packages such as NVivo can be used to help support data management and data analysis, I preferred to use manual processes of comparison and creating linkages though memoing and theorising, to ensure the nuanced, interpretive analysis of the researcher as advocated by Charmaz (2000:520) was not lost in analysis. Coding of data was undertaken as suggested by Charmaz (2006) utilising two phases; initial and focused coding, the process of analysis used within the research is illustrated in Figure 4 (Pg.82).
During phase 3 of data analysis I attended a two day NVivo workshop in order to make a decision on the advantages of using NVivo software to support my analysis. Discussions with other researchers encouraged me to explore the use of NVivo further as they highlighted that it may make stages of coding less cumbersome and easier to manage. Although the use of NVivo to aid data analysis was considered, I decided to immerse myself in the data to try and focus on the emerging conceptual ideas through manually coding the data into categories.
Figure 4: The Process of Analysis Used Within the Research

**Phase 1** (Year 1)
- 11* Interviews undertaken with adult nursing student participants.
- Manual coding of 3 transcripts using open coding to develop an initial coding framework. Coding of 3 reflective journals
- Review with supervisors and agreement of initial coding framework
- Focused coding of further 8 transcripts using constant comparison techniques. Coding of 4 reflective journals
- Development of focused coding framework

**Phase 2** (Year 2)
- Further follow up interviews with 9 adult student nurses and Focus group with 5 adult student nurses. Coding of 6 reflective journals
- Focused coding of transcripts and reflective journals using constant comparison techniques

**Phase 3** (Year 3)
- Further follow up interviews with 8 adult student nurse participants. Coding of 4 reflective journals
- Focused coding of transcripts and reflective journals using constant comparison techniques

**Phase 4**
- 6 month post qualification
- Follow up career destination theme with 8 adult nursing students (email follow up)

Theoretical coding – Constructing theory

*P12 family withdrew in Phase 1, interviews commenced in Phase 2
3.15.1 Constant Comparative Analysis

According to Charmaz (2006), a key factor in conceptual development is the constant comparison of data with data to ensure that the voice of participants’ is clearly maintained; Langdridge (2004:300) argues that it is the key process in grounded theory. Cresswell (2007:64) calls the constant comparative method of data collection and analysis as a zig zag approach. According to Holton (2007:277), regardless of which variant of grounded theory is chosen, constant comparative analysis is used throughout to determine if the data supports and reinforces emerging categories. As previously discussed, during the process I continually returned to both the data and analysis to impact on future data collection and analysis. Memo writing is associated with this process and was used throughout to capture my thoughts about the similarities and differences seen in the data. This stage was further enhanced through my research supervision.

The use of participants’ own language, as advocated by Elliott and Jordan (2011), during the early stages of analysis was used to assist the robustness of genuine concepts that emerged from codes drawn from data collection. An example of focused coding to support the development of categories can be found in Appendix 17.

3.16 Immersing Myself in the Data

As a novice researcher, the process of immersing myself in the data by listening to the interview recordings, revisiting transcripts, reworking the analysis as well as writing my thoughts and ideas in memos was extremely challenging and chaotic at times especially due to the volume of data generated. As a result of interactions with the data collected throughout the research process my ideas became more coherent and I started to make connections within and between the categories.

3.16.1 Memo-writing

Many grounded theorists consider that memo writing is pivotal in grounded theory as they may provide a link between data collection and development of theory (Charmaz 2006; Bryant and Charmaz 2007b; Birks and Mills 2011). Charmaz (2006) suggests that writing memos are where the researcher can stop and analyse ideas about codes and categories, enabling the researcher to analyse data early on in the research process. Furthermore Stern (2007), advocates that memos are the mortar holding the developing theories together. Charmaz (1990:1169) suggests, that:
Memo writing gives the researcher an analytical handle on the materials and means of struggling with discovering and defining hidden or taken for granted processes and assumptions within the data.

The process of memo writing enabled my engagement with the data, and as Charmaz (2006:82) suggests, this enabled me to explore what I had seen, sensed, heard and coded. I reflected that the process of memo writing enabled me to capture and explore my thoughts throughout the process of data collection and analysis. After each interview, memos were written to reflect thoughts and feelings in relation to what I had learnt from each interview and contained my impressions about participants’ experiences of their visits. I was also able to identify and document participants’ emotions which helped to provide meaning to participants’ experiences. As Strauss and Corbin (1998:13) suggests, this may enable:

The intricate details about phenomena such as feelings, thought processes and emotions that are difficult to extract or learn through more conventional research methods to emerge.

As a novice researcher this was crucial in helping analyse my ideas and help develop codes and emerging categories, a viewpoint supported by Hunter et al. (2011) who describes this process as liberating.

An extract from a memo written during the early stages of data collection (Phase 1):

There are many references to being and presence rather than doing – code emerging? A few of the students talked about how they feel different when they wear their uniform – uniform seemed important and appeared to be a powerful image of what being a nurse meant. They talk in terms of having authority when wearing their uniform. I sense that putting on uniforms became part of their professional persona that it may be used to help them to distance themselves from patients. Listening I sensed that they may be using their uniform almost like an emotional boundary to protect themselves from getting too involved. I sense vulnerability for some that they are not wearing their uniforms on their visits. In contrast to this, some of the students seem to suggest that they feel freer not wearing their uniform during their visits. I need to explore what they are experiencing and feeling to try and understand this more.

This memo, along with others, was used during analysis of the data. Using memos supported emerging categories such as adaptive thinking and connecting with others.

3.16.2 Coding Process

Charmaz (2014:120) advocates the researcher keep the following points in mind when trying to find categories from the data:

- Remain open
• **Remain close to the data**
• **Preserve actions**
• **Compare data with data**
• **Move quickly through the data**

I found these points really useful, especially in the early stages of the study, to help me to connect and interact with the data. As a novice researcher these points as well as the questions (Table 6), advocated by Birks and Mills (2011:96), were really helpful throughout the process of coding to help me to remain focused on the participants’ experiences and perspectives of their visits:

**Table 6: Questions to Guide Coding Process**

<table>
<thead>
<tr>
<th>What is this data a study of?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What is actually happening in the data?</td>
<td></td>
</tr>
<tr>
<td>From whose point of view?</td>
<td></td>
</tr>
<tr>
<td>What category does this incident indicate?</td>
<td></td>
</tr>
</tbody>
</table>

Birks and Mills (2011:96)

Initially I found the coding system confusing as I found that different names are attached depending on the describing researcher’s preferences, thereby reflecting Schreiber and Stern’s (2001) acknowledgement that coding can be confusing especially for new researchers. Glaser (1992) uses the term *open coding*, whereas Charmaz (2006) uses the term *line by line coding*, for initial coding. Despite these differences, Charmaz (2014) argues that the terms used are secondary to the overview of data to conceptualise notions and interpret participants’ tacit meanings.

The three levels of coding for constructivist grounded theory used (see Figure 5a, pg. 86) shows the progressive order followed from initial (line-by-line) coding, focused coding to theoretical coding, to provide a signpost to help with moving forward with data analysis. The data analysis process will be discussed next with excerpts of interview transcripts to convey participants’ subjective meanings.
3.16.3 Initial Coding (line-by-line)

According to Corbin (2015) analysis is more than coding, he argues that writing, reflecting, rewriting, re-reading the data, re-reflecting and re-rewriting is essential. Coding of emerging data was undertaken as it was collected, enabling me to start to define and categorise the data. As recommended by Charmaz (2006), transcripts were coded line-by-line and used to study emerging data and conceptualising ideas. Starting with the words and actions of participants provided a way of looking at their experiences, an approach supported by Charmaz (2006:49), who argues that if participant’s meanings and action are glossed over then, rather than reflecting the insiders view the grounded theory will reflect the outsiders view. As Charmaz (2006:55) suggests, line by line coding can help the researcher to: see the familiar in a new light, and can help to avoid arriving at ideas prematurely. Hence the initial codes incorporated participants’ own words which enabled me to remain open to the data. Bryant and Charmaz (2007) suggests that using quotes in the findings reflects the constructivist principle of keeping the participant’s voice prominent in the research. As tentative categories emerged from coding transcripts lines of enquiry emerged. This enabled subsequent interviews and focus group to be more focused exploring emerging categories utilising open-ended questions as I started to follow leads provided by participants into next interviews. Interviewing participants over 3 phases gave me an opportunity to revisit emerging categories with them, by using cues from
their previous interviews. An example of this is whereby some participants mentioned concerns regarding ending their relationships, consequently in phase 2, I added a prompt about *concerns about ending your visits?* The interview guide was changed to reflect the evolving focus of the questions to enable me to explore emerging categories over each phase of study (Appendix 11). If participants responded with interest I would draw them out further, however, if they did not I did not pursue it further.

### 3.16.4 Focused Coding

Focused coding is, according to Charmaz (2006), the next step in the coding process and as Engward (2013) suggests, pinpoints the most frequently occurring initial codes to synthesise and organise large volumes of data. To try and ensure that the nuances of the student experiences had not been missed, I re-evaluated the initial codes against the original scripts. Initial codes were grouped into emerging focused categories, which Birks and Mills (2011) describe as being the same as concepts. As Charmaz (2006) suggests, categories are themes which aim to try and make sense of what the participants have said and were used to explain ideas and processes in the data. In keeping with the method of grounded theory, early categories were considered provisional and open; as ongoing comparative analysis and conceptualisation continued changes were made to the initial coding. An example of this can be seen in Appendix 20.

### 3.17 Theoretical Coding

According to Charmaz (2006) the purpose of theoretical coding is to indicate possible relationships between the categories that develop during focused coding. The main categories identified from my focused coding are discussed further in Chapter 4. During the theoretical coding procedure I transferred focused codes to post-it notes and sorted into major categories (theoretical codes). I found writing the major categories on post-it notes helped me to reflect on the relationships between them, Figure 5b (pg. 88), to help develop theoretical codes as illustrated in Figure 5c (pg. 88).
Figure 5b: Theoretical Coding in Action: Poster of Building of Relationships

Figure 5c: Theoretical Coding in Action: Components Related to Building Relationships
3.18 **Achieving Saturation or Theoretical Sufficiency**

Data collection and analysis continued until saturation was reached (Charmaz 2006). Hutchinson (1986:25) describes saturation as:

> …the completeness of all level of codes when no new conceptual information is available to indicate new codes or the expansion of existing ones. The researcher, by repeatedly checking and asking questions of the data, ultimately achieves a sense of closure.

Review of the literature highlighted that there appears to be minimal guidance or tests of adequacy, to determine either sample size or how much data is needed to achieve saturation in constructivist grounded theory. Charmaz (2006) and Dey (2007) both challenge the notion of whether it is achievable to reach saturation and instead prefer the term theoretical sufficiency, suggesting that this indicates that adequate data and fullness of coding has been achieved. Charmaz (2006:114), contends that saturation could in fact be an artefact of the way researchers focus and manage data collection. Furthermore she points out that assumption of theoretical saturation is also noted as a common hazard affecting grounded theory rigor (Charmaz 2006). Additionally Dey (2005), posits that in an emergent methodology such as grounded theory saturation is not truly possible, suggesting that researchers often use the term to justify smaller sample sizes. Constructivists acknowledge that theory represents one explanation rather than a discovered truth (Bryant and Charmaz 2007).

Although it was necessary for the study to be representative, there was a risk that if a lot of data was collected that it would not be analysed and consequently fundamental processes lost. To achieve data sufficiency data collection continued until there were no new theoretical insights. Initially the plan was to conduct interviews with students prior to visits with follow up interviews in years 1, year 2 and year 3, to enable me to follow the students’ perceptions of their experiences over time. As previously discussed, interviewing participants over 3 years enabled follow-up of any major ideas, as well as provide opportunities to explore and refine the categories, whilst checking ideas by moving back and forth between the categories and data. A time line was developed to plan key milestones within the research and help to keep the research on track (Appendix 21). This was particularly important as I was working full time and studying for my PhD part-time.

3.19 **Theoretical Sampling**

Interviewing the same participants over 3 years provided opportunities for me to follow-up and explore emerging ideas and categories. Charmaz (2006) identified that subsequent interviews
can allow for theoretical sampling to address conceptual issues and strengthen rigor. I found the process of theoretical sampling enabled me to refine and develop emerging categories. As recommended by Charmaz (2006) the process involved moving back and forth between category, data checking and refining ideas (Figure 3, pg. 62). Memos also helped me to explore emerging ideas.

3.20 Conceptualisation

Core conceptual categories were identified from the initial coding categories as suggested by Charmaz (2006:47). These categories were developed through repeatedly moving back and forth between the data. To help me with conceptualisation; action and analytical questions were repeatedly used through the process as advocated by Charmaz (2008:161):

*What is happening here? …and what theoretical category are these data a study of?*

3.21 Ethical Considerations

Researchers are committed to respect the human rights of participants to avoid causing harm, based on the ethical principles of human dignity and justice (Gallagher and Hodge 2012, Polit and Hungler 1999). Additionally nurses must always practice within the standards of the NMC (2015) Code of Conduct. It was essential that I address my relationship with participants, as a member of the teaching faculty I had a dual role as researcher and teaching fellow of the adult nurse student participants.

The study was reviewed and granted a favourable ethical opinion by the University Ethics Committee of the University of Surrey, UK (Appendix 15). According to the National Health and Medical Research Council (2001), vulnerable groups are usually seen as people with mental or physical impairment and the very young and old. It could be argued that students may also be considered a vulnerable group, as they need to be feel able to decide to participate without fear of repercussion (Raja-Jones 2002). Bradbury-Jones and Alcock (2010) discuss this in terms of *I’ll do it if it helps*, they reinforce the importance of student nurses understanding both the purpose of the study and their contribution to future knowledge. As Moore and Millar (1999) advocates, students should not be used because they are convenient, arguing that they should only be used if the research question(s) relate directly to them. The *Time for Dementia* programme was incorporated into the curriculum for all adult nursing students, consequently the research question directly related to them as they were participating in the programme of visits.
Although nursing students are essential participants in this study, the challenge for me was to ensure that the process of involving them was done in an ethical manner which did not compromise their privacy and dignity. According to Edwards and Chalmers (2002) this places the nurse educator conducting the research in a position of dual agency. I acknowledged that there may be potential abuse of power due to the researcher’s dual role as researcher and teaching fellow of the adult nurse student participants. The primary concern with respect to the nursing students invited to participate in the study was the concern that they may not feel free to refuse to participate especially as the researcher is a member of the faculty with whom they have an academic relationship. Ferguson et al. (2006) suggests that students may fear poorer learning opportunities and may be disadvantaged if they do not participate. On the other hand, Eide and Khan (2008) and Bradbury-Jones and Alcock (2010), argue that some students may feel more confident participating in research with a known member of academic staff.

It was essential to address concerns related to the duality of my role as researcher and member of the teaching faculty as students may feel subtle pressure to participate in research, under people who have some control over their academic future. Potential participants for the study were provided with consent form (Appendix 4 & 5) and a participant information sheet (Appendix 7 & 8) which set out the aims of the study and made it clear that any refusal or subsequent decision to withdraw would not lead to discrimination (Polit and Hungler 1999). The title researcher was put on consent forms and information sheets to reinforce my role as researcher rather than my role in the faculty as teaching fellow to try and help students to understand that the relationship differed from the usual relationship they had with me.

Participants were given assurances prior to each interview about the ethical principles of anonymity and confidentiality. Confidentiality and anonymity was maintained through allocation of subject numbers (PX) and the secure handling and storage of data in accordance with the requirements of the University and faculty ethics committee. Participants were allocated the prefix P and a number, for example P1. Transcribed interviews were stored with the filename format (PX, Phase X). For example: (P1, Phase 3) denotes participant 1 in phase 3 of the study. Reflective journals were stored securely as hardcopies and identified by (PX). The focus group interview during phase 2 were stored (FGX). Participants’ visit information is summarised in Appendix 9. It was also important to acknowledge the potential conflict between maintaining confidentiality and duty of care to students. This ethical and professional conflict may potentially arise from students disclosing information in interviews that may breach their Code of Professional Conduct (NMC 2015). Participants were informed that any concerns would be addressed in the study through the application of the University’s escalating concern guidance.
Another issue that had to be addressed was that of conflict of interest. As previously highlighted my PhD was funded from a larger *Time for Dementia* project funded by Health Education England Kent, Surrey Sussex. Participants were fully informed of the funding in the participant information sheet (Appendix 6 & 7).

3.22 Rigor

The concept of rigor is synonymous with quality. Beck’s (1993) framework including the standards of credibility, auditability and fittingness is frequently used as standards of rigor in qualitative research. Furthermore Guba and Lincoln (1989) suggests that a study is credible when it presents such as vivid and faithful description that people who had that experience would immediately recognise it as their own. Credibility of the emerging concepts was evidenced by changes made during the research study, such as changes to the prompt questions asked as data collection proceeded and checking of emerging categories as data continued over the three phases of collection.

Charmaz (2006), suggests that rigor in constructivist grounded theory encompasses credibility, originality, resonance and usefulness. Charmaz (2006) contends that to maintain credibility in constructivist grounded theory reflexivity is needed. An outline of the reflexivity incorporated throughout the study can be found in Chapter 1. The process of reflexivity not only increased my self-awareness, it also helped to outline decisions taken during my study. Additionally to try and ensure credibility in the data, checking with my supervisors took place regularly within each phase of the study, especially as categories were developed to try and avoid forcing construction of core categories. This helped to verify construction of core categories. As previously discussed, memoing was used throughout the study as a tool to record my thinking throughout the collection of data and during analysis of the data. Extracts from the memos can be seen in Appendix 18 & 19. The validity of emergent conceptualisations were constantly checked through the use of constant comparative method. A return to the literature in the later stages of the study and comparison of the study findings was made with the literature helping to strengthen validity of the findings. To further enhance credibility of the developed theory the researcher ensured detailed description throughout the study including participant quotations in the write-up to evidence emergent categories in order to promote credibility as well as transferability of the research. Charmaz (2006) suggests that if researchers can offer new or broader understanding of the phenomena being studied, research may make a contribution to knowledge that is original. As previously identified in Chapter 2, there is a lack of literature involving people with dementia in adult nurse student education nationally or internationally.
The mandate by Health Education England to include dementia in undergraduate nurse curricula from September 2015 made it timely to explore an innovative dementia educational intervention like *Time for Dementia*. Charmaz (2006:182) suggests that researchers ask themselves:

*How well will the findings resonate for participants?*

As previously discussed dementia is mandated in pre-registration nurse curriculum therefore as educators it is essential that dementia is facilitated in a meaningful way that engages with people with dementia, helping nursing students’ to link theory and practice to improve dementia practice (Daley and Grosvenor 2016). Resonance was demonstrated through the findings of the study which adds to the evidence that involving people with dementia in education is a valuable learning resource for adult nursing students. Although adult nursing students are the focus of this study, it could be argued the findings are relevant to healthcare educators in a variety of disciplines of healthcare.

### 3.23 Gaining Access and Recruitment

As a researcher, educator and nurse I had a responsibility to ensure that participants’ best interests were protected. Mechanisms were built into the research process to try and address the power differential between the researcher and students. All written communication with students who met the inclusion criteria, such as emails inviting them to participate in the research process, was facilitated by the administrator for the wider *Time for Dementia* project. This was done to try and distance me from the recruitment process. Any adult nursing student who expressed an interest in participating in the study were provided with a participant information sheet (Appendix 6 & 7). The Participant Information Sheet (PIS), enabled participants to understand what the research involved and clearly identified: their role, level of participation, as well as possible risks and benefits. Contact details of the researcher were included on the participant information sheet to enable students’ to contact the researcher if they wished to discuss further.

The Participant Information Sheet (Appendix 6 & 7) and consent form (Appendix 4 & 5) were discussed with the participants at the beginning of each interview in order to review the purpose of the study, potential benefits and the right to withdraw at any time. It was also an opportunity to reinforce that as participants they were the *experts* in the study as they owned their experiences and what meanings they learnt from it, and I was appreciative of their participation. As Greaney et al. (2012) advocate, demonstrating respect to participants’ at the recruitment
stage and afterwards can be viewed an important part of the research process. Rubin and Rubin (2005) suggest that it may also help to balance the power differential between participants and the researcher. It was important to me to clarify that I was not there in my role as a member of the teaching faculty, my role was that of a researcher and my interests lay in listening to their perceptions of their experiences of the visits. To reinforce my role throughout the study any discussions or documents pertinent to the research I referred to myself as the researcher. Another approach to try and help balance the power differential was to try and schedule interviews around the participants’ availability. As previously discussed it was essential to try and ensure that participants viewed the interviews as a joint and collaborative production. As the interviews progressed I wrote in my memo:

I feel so privileged to be party to the reflections of students’ experiences of their visits …I need to ensure that I represent their voices within the research. As the interviews progress I feel that my role within the faculty ceases to matter as participants seemed to feel confident to share their experiences and perceptions of their visits.

3.24 Introducing the Theory of Whole Sight and its Model

As previously discussed, data were collected over 3 years using annual semi-structured interviews, reflective journals, focus group, memos and consistent with a constructivist grounded theory approach, literature was also recognised as a source of data (Figure 6, pg 94). Glaser (1978) suggests that the basic grounded theory question driving a grounded theory study is: what is happening here? Charmaz (2011:11), also proposes that as questions are a central part of using grounded theory and integral to understanding of the inquiry that it is:

Essential that grounded theorists study their data as well as studying their interview questions.

As potential categories began emerging from coding interviews in phase 1, further areas for exploration emerged. As the data collection progressed, the interview guide was revised to reflect participants’ responses and shape the open-ended prompts in phase 2 and 3 interviews (Appendix 11) and focus group (Appendix 12). As explored in Chapter 2, returning several times to participants for further information through follow up interviews in phase 2 and phase 3, is congruent with a constructivist approach (Bryman 2008; Silverman 2010). As Charmaz (2000) suggests, it also enabled participants to talk about what was important to them about their experiences. An extract from one of my memos during phase 1, demonstrated how I felt that the emergent journey was unfolding:

As participants were telling their story, interviews could also be seen as an unfolding story shaped by the participants which focused subsequent interviews
Throughout the analysis of the data, the approach adopted by Locke (2007:575) was taken, which calls for the researcher to ask the grounded theory question, *what is going on here?* Data is viewed as constructed rather than discovered, and according to Charmaz (2009:131):

*Analyses are interpretive renderings and are not seen as the only viewpoint on the topic.*

Participants of the study eloquently discussed their experiences of visiting people with dementia and their carers; sharing their perceptions of their learning about dementia as well as impact on their professional practice.

The method of constructivist grounded theory was considered a suitable approach for this study, staying open to the data enabled me to follow the path illustrated by the data to enable the perspectives of the participants to emerge. Figure 6 (pg. 96), illustrates the analysis process showing coding, category development and the resulting emergent theory.
Research Question: What are adult student nurse perspectives on the impact of longitudinal home visits to people with dementia and their carers?

Participants’ recruitment: First year adult nursing students (September 2014) involved in Time for Dementia programme visits

Data collection: interviews with adult nursing students. Phase 1 ($n=11$); Phase 2 ($n=9$); Focus Group: ($n=5$); Phase 3 ($n=8$). Reflective Journals, memos and literature

Initial Coding

Focused Coding

Sub Categories:
- Adaptive Thinking, Building Relationships, Transformative Learning

Core Category: New Ways of Seeing

Theory: Whole Sight
3.25 **Summary**

This Chapter described how data were generated rather than merely collected, which is appropriate to the constructivist approach used within this study. Justification for the research methods in this study were appropriate to meet the aims of the research study. Alternative approaches for generating qualitative data and the rationale for the selection of interviewing as the main qualitative approach chosen was also discussed. This approach underpinned the emphasis of this study on understanding and the importance of the experiences and meanings of participants rather than prediction. As the researcher I am part of the world of the study, with meanings created from shared experiences and relationships with the student participants' consequently my observations provided another source of data. As previously discussed, constructivist grounded theory provided the framework used to guide the process of analysis and excerpts from interviews, my observations and the literature are integrated into the discussion of the findings. This Chapter also considered the ethical issues related to this study and the measures taken to try and reduce the risk of harm to participants were also explained.

The next Chapter presents the findings that emerged from analysis of the data and addresses how the aims and objectives of the study were met. The first section of the Chapter presents the findings from the analysis of the reflective journals of participants' visits. The next section explores the process of how the new theory of *Whole Sight* was identified, followed by the emergence of the core category of *New Ways of Seeing* and its related sub-categories of: *Adaptive Thinking, Building Relationships* and *Transformative Learning*. The final section of this Chapter provides an overall summary and discussion of the theory of *Whole Sight*, existing literature is integrated throughout to strengthen rigor.
4 Chapter 4: Development of the Theory of *Whole Sight*

4.1 Introduction

This Chapter presents the findings that emerged from the analysis of the data and the theoretical conceptualisation of adult nursing students’ perceptions of their visits with people with dementia and their carers and addresses how the aim and objectives of the study were met.

**Aim:**

The aim of this study was to explore adult nursing students’ perceptions of their experiences of visiting people with dementia and their carers over 3 years and the impact on their professional learning and practice.

**Objectives:**

1. To explore adult student nurses’ experiences of visiting people with dementia and their carers at home
2. To understand how contact with people with dementia and their carers impact on students’ understanding of dementia
3. To explore if and how regular contact impacts on care practice

Chapter 5 (pg. 174), addresses how objective 4 of the study was met:

4. To look at nursing students’ perceptions of the impact of the visits on their future career choices

The first section of this Chapter presents the findings from the analysis of the reflective journals of participants’ visits. The next section explores the process of how the new theory of *Whole Sight* was identified, followed by the emergence of the core category of *New Ways of Seeing* and its related sub-categories of: *Adaptive Thinking, Building Relationships and Transformative Learning*. Each major finding is discussed in a subsection in this Chapter, followed by discussion supported by relevant literature. In keeping with a constructivist grounded theory methodology, following the initial scoping literature review that identified gaps in the literature, an ongoing dialogue between the categories arising from my analysis and findings, and the literature was undertaken. The discussion integrated this literature with my own research.
findings, this led to an emerging theory of the impact on adult nurses’ professional learning and practice, resulting from their longitudinal visits with people with dementia in their homes.

Extracts of interviews and the focus group are used throughout the discussion to clarify the process of emergence of the theory, core category and related sub-categories and demonstrate that the theory and its related categories are grounded in the data. The final section of this Chapter consists of an overall summary and discussion of the theory of *Whole Sight*, existing literature is integrated throughout to strengthen rigor.

### 4.2 Introducing the Theory of *Whole Sight* and its Model

Glaser (1978), recommends using a graphical representation of the theory to help with writing-up, suggesting that it helps the researcher to improve understanding of the theory.

Figure 7 (pg. 100), is a graphical representation of the emergent theory of *Whole Sight.*

*Whole Sight* represented the pattern of behaviours that resulted from participants’ visits to people with dementia and their carers. The theory of *Whole Sight* is built around the core category of *New Ways of Seeing*, and is representative of the impact of longitudinal visits to the homes of people with dementia on the participants professional learning and practice.
Figure 7: Impact of Student Nurses’ Learning from People with Dementia and their Carers

THEORY: WHOLE SIGHT

New Ways of Seeing

Core Category

Adaptive Thinking

Building Relationship

Transformative Learning

Being Challenged

Seeing Hope

New Insights – Carer
- Maintaining couplehood
- Perceptions of loss

Learning about Oneself
- Uniform & Identity

Being Present

Making A Difference

Attachment & Reciprocity

Authentic Connections
- Friendship
- Genuine Dialogue
- Ending Relationships

Empathetic Learning

Emotional Learning
4.3 Findings and Discussion: Reflective Journaling

4.3.1 Introduction

This section presents the findings of reflective journals of participants’ visits, to enable further exploration of their learning in relation to the impact of listening to a person living with dementia and their carer. Evidence of participant learning was apparent when reading their journal entries. Entries reinforced the benefits of the serial nature of the visits, repeated and regular contact appeared to enable participants to gain a more holistic view of the person with dementia and their carer. Journal entries helped to illuminate changes in participants’ perceptions and attitudes towards dementia. Entries reflected and reinforced the main categories identified through the interviews, providing insights into participants’ increasing self-awareness and learning about dementia. The following interconnected categories were identified from analysis of the participants’ reflective journals, suggesting that they learned about: Valuing Relationships and Increased Awareness of Self which contributed to Seeing the Person rather than just seeing their dementia (Figure 8 pg.101).
Figure 8: Experiences of Visits As Described by the Participants in Reflective Journals:

4.3.2 Valuing Relationships

The reciprocal nature of the visits engendered by the project emerged as a core theme within all of the participant’s journal entries. At a fundamental level their enjoyment and appreciation of visits was reflected in their writing as they recognised the significance of developing relationships:

*Amazing spending time with them both. (P8)*

*Felt privileged to be part of their lives. (P1)*

*Overriding emotion – happiness, family enjoyed having time with us and being able to speak freely about the issues. I am happy to see how well people can live and manage at home. (P4)*

Participant 1 recognised how they could make a difference simply by listening, enhancing the value of developing therapeutic relationships with people with dementia:
Biggest impact for me has been the realisation that sometimes people do not want answers, they just want people who will listen […] Realisation of how important human interaction is. (P1)

There were numerous entries by participants’ describing the significance of the relationships that they had developed with the person they were visiting and their carer. This appeared to lead to an appreciation of the value of relationships and the contribution of these relationships in supporting the person to live well with dementia:

His wife shared that the visits gave an outlet to her feelings, she confided she was unable to share her fears with her family as she had to ‘protect their feelings’. This made me feel that we were sharing something special. (P10)

Many of the participants commented on how open and receptive both the person with dementia and their carer were in talking about the impact of dementia on their lives. They described how this enabled them to gain a unique understanding and insight of the impact of dementia on relationships.

She (wife) shared with us how she felt that she was losing her husband to dementia. Impact of lost shared memories – clearly difficult for his wife […] she could not bear to think about no longer being able to care for her husband at home. (P10)

It was emotive listening to her talking about her transition from wife to full time carer, she missed being his wife. She talked about loss a lot, like she was grieving. (P5)

One of the participants wrote about her observations on changing relationship of mother and son:

Son had taken on role of her carer. The impact that this had on his relationship with her is that that it seems to have become his ‘job role’ rather than visiting her for pleasure. This made me feel sad - overwhelming sense of loss (P7)

Participant 1 wrote about their observations of the impact on the person and their carer discussing how they had to wait for months before getting a diagnosis of dementia:

Label of dementia – it suddenly became real for them, they both had to face up to it; their lives and future was going to be very different to the one they had planned. (P1)

She later wrote about how this made her feel, reflecting on feeling a sense of loss but also a sense of hope that they were, trying to make memories by going on holiday while they still can.

There were numerous entries in participants’ journals, describing how appreciative they were of the ways in which the older person with dementia and their carer created a positive learning environment; being open and receptive, which combined to result in a high level of respect:
They were so open and honest, opening up their lives to us and sharing their journey - a privilege to be part of. [...] 100% will stick with me, made me consider my practice and try different approaches to communication and care delivery. (P2)

Sharing their dementia journey, its life changing and helped me change my perspective of dementia and focus on the person in my practice. (P8)

Made me begin to understand the massive effect that dementia has, particularly on the carer [...] something I will take away and be considerate of in my practice. (P5)

Participant 8 wrote about the personal impact the relationship she had developed as:

Making me proud to become nurse.

4.3.3 Increased Awareness of Self

Completing the reflective journals appeared to stimulate participant’s awareness of their practices and how they related to older people with dementia and their carers. Some of the participants wrote about how their interactions and developing relationships resulted in reflections on bias and stereotypes of dementia that they had observed.

People with dementia do not want to be labelled as that is not who they are. In practice people with dementia are often labelled as demented and difficult [...] referred to as dementia patient or by their bed position rather than by their name (P2)

Learnt a lot about care and the impact of poor practice by listening to them. (P8)

Journal entries provided many valuable insights into how experiences of the visits may influence the participants’ current and future practice with people with dementia and their carers.

Experience helped me to develop confidence and new skills in how to communication and listen, main thing - important to find out about the person and family (P8)

Important to find out how carer is, to remember they are the expert. (P10)

Many of the participants described the impact in terms of increasing their confidence:

As a result of my experiences (visits) I feel I am much more confident in caring for people with dementia. (P1)

Reflecting on my experiences of the visits, I feel much more confident and find it easier to talk about dementia whilst in practice. (P5)

Increased my confidence in communicating with people with dementia and carers. I now feel confident in starting conversations and trying different approaches. Important to not to be afraid to try. (P8)
Participant 1 reflected how *listening to support someone and being with is just as important as doing*.

There were many journal entries which illustrated the impact, both personal and professional, that the visits had on the participants as they reflected on their experiences:

*To see the pride and joy in her (person with dementia) eyes when she was talking about her life, that made me proud to be a nurse and think about what kind of nurse I want to be.* (P8)

*It was a privilege to be part of their journey, listening to them both talk about their lives and how they support each other.* (P5)

*Visits touched my heart and made me feel part of their journey.* (P10)

*Put things into perspective for me, made me appreciate my life more.* (P1)

Participant 1 related to the person with dementia and their carer with their own family and ‘self’:

*Couple have no family. I found it hard to relate to as I have a large family. Related to my own grandparents and how they too had become housebound – felt guilty, wished I had done more for my own family, made me feel quite emotional.* (P1)

Some of the participants wrote about how the visits encouraged them to want to learn more about dementia, drawing on literature and demonstrating that they were able to make connections to help link theory and practice.

*I wanted to learn more about the type of dementia X had so I found some information and read up on it more, the symptoms and causes of it. It was really interesting as I was able to link what I had read to what I was seeing on the visit.* (P10)

*Read about dementia before our first visit to help prepare as not had much experience of dementia.* (P4)

*I explored what support was available for carers and people with dementia in the community.* (P8)

### 4.3.4 Seeing the Person

All of the participants reflected how their interactions during their visits had caused them to see older people with dementia in a different way. Repeated and regular visits appeared to enable participants to view the person with dementia more holistically; perspectives appeared to change from focusing on the person and not their dementia:

*Good to hear about their lives before the diagnosis and not concentrate the visit solely on dementia.* (P10)
People with dementia don’t want to be labelled as that is not who they are. (P2)

How dementia affects people differently…impacts on the person and family/caregiver in different ways, which I did not really consider before. (P1)

The longitudinal nature of the visits enabled participants to observe the changes in the person as their dementia progressed and their perceptions of the impact this had on carers. Participant 2 described how they had observed a deterioration in just 7 weeks since their previous visit. She wrote how his wife shared with them that she was struggling and how a recent visit to her brother-in-law, who also has dementia, had really affected her as his brother did not recognise either of them and she worried more about the future. Participant 2 described her observations of the impact of this:

Noticed a difference in the wife’s towards her husband and how she seemed to be easily annoyed by him. She seemed to have distanced herself from him.

This left the participant with feelings of sadness, which contrasted with their observations during their previous visits whereby both she and her husband had:

Seemed positive and optimistic regarding his dementia diagnosis and the future.

Some of the participants identified the benefits of the longitudinal aspect of visits themselves:

Interesting to see the noticeable changes between visits […] the benefit of the long nature (of visits); we usually just get to see a snapshot of peoples’ lives rather than changes over time and how they adjust. (P1)

Sharing their journey, seeing how dementia impacts over time, we never get to see that in practice. It has been life changing. (P2)

When we first went I would not have known ‘X’ had dementia, over time changes became more prominent. (P5)

Many of the participants reflected in their journals and interviews how they had gained new insights into dementia through spending time talking and listening to a person living with dementia and their carer:

Person is more than their dementia, it is important to know about their lives – helps me to engage. (P5)

Listening to them, you get their personal story and the impact it has had on them. They are both living with dementia, not really thought about it in that way before. (P8)

Brought living with dementia to life, you can read about dementia but it is not the same as listening to a person living with it…seeing the changes over time for both of them and how they have to adapt their lives. (P1)
Participants wrote about how they were moved to learn more about dementia and the support services available, demonstrating an appreciation of their own responsibility to broaden their knowledge base if they are to be as effective as possible in their work with people with dementia:

I wanted to find out more about singing for the brain as both discussed their enjoyment at attending. Made me aware of the importance it is to signpost people to ‘different’ services and explore what’s available…it’s not always that easy to find. (P10)

After the visit, I wanted to learn more about their dementia and compare the symptoms to what I was observing. Really interesting, often the focus is on memory loss but there is so much more that, how it really impacts on daily living. (P5)

4.3.5 Summary: Reflective Journal Findings

Using reflective journaling to support student learning is frequently used within adult nursing to try and encourage them to explore their understanding of experiences especially in placements (Epp 2008; Davies et al. 2013; Reitmaier et al. 2015). Epp (2008) suggests that it can help students to gain new insights which they may not otherwise recognise without the process of reflecting on the experience. However, Davies et al. (2013) asserts that much of the evidence of the value of using reflective journals in nurse education is anecdotal, citing that there is a lack of studies evaluating their effectiveness. Although participants were asked to write an entry after each visit this was not always completed by everyone after every visit. When questioned about the use of the journals, the majority of the participants stated that they preferred to talk about their experiences with their student partner who accompanied them on their visits, rather than write in their journals. Some of the participants felt that they benefitted from reflecting with their visit partner or during their interviews, participant 5 stated that they could express their feelings much more freely in discussion rather than writing in their journal. Exploration of the use of journals and students’ attitudes towards completing journals is also an area that would be interesting to explore at a post doctorate level.

Analysis of the data from reflective journals suggests that sequential visits challenged existing stereotypes and helped to challenge students’ beliefs about dementia. The categories identified confirm and support the categories that emerged from the data analysis of interviews over the three phases of the study and focus group (phase 2). Comments included in the journal entries supported the interview data that the participants found the visits positive experiences. Although it has to be acknowledged that there is a possibility that the entries reflected socially desirable reflections by the students as they knew their entries were being read by a member of the faculty, entries were supported by the interview data over the three
phases of data collection and the focus group (phase 2). Despite the limited number of reflective journals completed, I wrote in a memo that:

*They provided further insights into how students seemed to benefit from the contact, reinforcing the mutuality they felt within the intergenerational relationships they had developed with the person with dementia and their carer over time.*

Changes in participants’ perceptions related to dementia were illuminated in the journal entries as they found out more about dementia and the impact on the person and carer. These findings correlate with Davies et al. (2013) study which explored the experiences of nursing students’ visiting older people living in the community, they also reported that students reported that they had learnt more about the ageing process and its impact on the person as a result of their visits.

The interconnected categories identified from analysis of the reflective journals provided insight into participants’ increased self-awareness and new ways of seeing the person with dementia. Findings reinforced the emerging core category of *New Ways of Seeing* and development of the theory of *Whole Sight*, which is discussed in the next section.

4.4 Finding and Discussion: Context and Conditions of Whole Sight

4.4.1 Introduction

The following section explores the process of how the new theory of *Whole Sight* was identified, followed by a discussion of the emergence of the core category of *New Ways of Seeing* and its related sub-categories of: *Adaptive Thinking, Building Relationships* and *Transformative Learning*.

4.4.2 Identifying Theory and Integrating Existing Theory

The impact of using sequential interviews with the same participants added depth and resonance to participant’s stories, to help produce a *fuller story*, as experiences of their visits and relationships developed over the course of 3 years. The approach used meant that I was able to follow up on the emerging categories over each subsequent phase, enabling me to feel as though I was immersed in participants’ experiences. I recorded in my memos that I noted that many of the participants used the phrases, *Whole Sight* and *Whole* during data analysis. These phrases seemed to describe the changes to their perceptions of dementia as a result of their visits, asserting that people with dementia should be treated as *wholes* with attention given to their lives and relationships:
See visits as helping to aid me develop as a caring nurse…importance of seeing and working with the whole person…**whole sight** I suppose. My confidence and my attitude has changed dramatically with dementia patients [...] you don’t mean to but you play ignorant because you don’t really know, the more you do know and the more you’re exposed to it you just have more time and understanding [...] my perception of dementia has changed for the better […] listening to both the person with dementia and their carer…life changing (P7, Phase 2)

There should be less Taboo about dementia…Programmes such as Time for Dementia gives the opportunity to slowly face our misconceptions about it and gives the new generation of healthcare professionals a better understanding of how to go about approaching dementia as a **whole** focus on the person (P12, Phase 3)

…they still have a lovely life, they go on holiday and stuff…if I hadn’t seen it I wouldn’t have believed that there were any positives in dementia. I think the project’s good, it does make you see the **whole** picture, whereas when you’re in practice you focus on the treatment […] you only get a snapshot of dementia. (P2, Phase 3)

What emerged from the data was the development of the theory of **Whole Sight**, which encompassed the perceived impact of the visits which resulted in participant’s **New Ways of Seeing** dementia. I found that the theory of **Whole Sight** joined the previously separate concepts together into a **whole** that I could construct into a diagram to explain my findings. A graphical representation of the theory of **Whole Sight** was developed to help me with the process of writing up, as suggested by Glaser (1978) (Figure 7, page 100). Findings suggest that as a result of their visits, participants reframed their perceptions of dementia, as attention was given to broadening their view of dementia to encompass the person’s lives and relationships, seeing and treating people with dementia as **wholes**, and not just focusing on their dementia. Intergenerational relationships were built with people with dementia and their carers, consequently participants’ viewed the person more holistically, which resulted in participants’ adapting their thinking about dementia. The theory of **Whole Sight** also represented the participants’ personal and professional growth as adult student nurses over their 3 years of study.

The **Whole Sight** theory is built around the core category of **New Ways of Seeing**, which began to emerge in phase 1 of the interviews and continued to emerge throughout phases 2 and 3. During phase 2, I made a note in one of my memos that:

*participant’s frequently refer to whole, whole sight and new ways of seeing dementia to describe their experiences, the importance of seeing the whole person and not just their dementia is becoming much more evident.*
4.5 The Emergence of the Core Category of *New Ways of Seeing* and its related Sub-categories in the Theory of *Whole Sight*.

Analysing data continuously and critically challenging my interpretations by returning to the original transcripts as advocated by Strauss and Corbin (1998), allowed the core category of *New Ways of Seeing*, to emerge from the data. Staying open to the data enabled the adult student nurse participants' perspectives to emerge as much as possible (Glaser 2011). *New Ways of Seeing* reflected the participants' new understanding of dementia that resulted from their visits, and represents the core category of the emerging theory of *Whole Sight* and its related sub-core categories (Figure 7, page 100). Glaser (1978:94) defines the core category as:

> The main theme for what in their view […], sums up a pattern of behaviour the substance of the what is going on in the data […] which brings out process and change.

Strauss (1987), contends that an emergent core category can be identified in the data by its numerous recurrences and its essential relevance in relation to other categories that are identified in the analysis of data. *New Ways of Seeing* represented changes to participants’ perceptions and understanding of dementia. It also represented the participants’ journey of making sense of what being a nurse meant to them. The core category and subcategories are presented in numbered sub-sections, followed by a discussion supported by relevant literature. Both Glaser (1978) and Strauss and Corbin (1998) suggest integrating the literature directly into the findings, that is handling literature as *data*, arguing that integrating relevant literature to findings helps to increase rigor of the study.

4.6 Core Category: *New Way of Seeing*

*New Ways of Seeing* was evident throughout each of the 3 phases of data collection, it summed up the pattern of behaviours and illustrated the process of changes that resulted from participants experiences of their visit, leading to *Whole Sight*. This core category was reinforced by participants’ self-examination, frequently illustrated throughout their discussions as they recognised their new understanding of dementia, consequently their assumptions about living with dementia were challenged. As participants faced their assumptions of dementia, findings suggest this resulted in greater participant self-awareness of the importance of *seeing the person* rather than their dementia. Participants frequently expressed how they were inspired to see beyond the persons’ dementia, as a result of listening to the person, their
perceptions of living with dementia became more individualised. Visits enabled them to see them as individuals, with lives and experiences beyond dementia.

*I feel like listening about dementia in the media for example I don't really get that much of an insight. I feel like lectures and reading is a lot different from going and experiencing it […] to actually imagine it and get a better insight you need experience which I think has changed my insight into it – I know much more about dementia from listening and seeing… the experience has definitely changed my insight of dementia. See the person as a whole… gave me new ways of seeing dementia. (P9, Phase 1)*

*Completely opened my eyes and changed my mind-set about dementia. They still live life to the full […] see dementia in a new way as a whole rather than just a disease. (P2, Phase 3)*

The ability to position and see people with dementia as individuals rather than patients seemed to be the first step in enabling participants to understand dementia within social contexts. All of the participants demonstrated a heightened awareness of the uniqueness of dementia which seemed to enable them to consider the wider experiences of people with dementia. As a result of their experiences participants demonstrated that they were able to see beyond the clinical issues of dementia that they perceived was the focus of care delivery in hospital, to encompass the wider context of considering the impact on the person and their carers’ lives, enhancing the development of seeing patients as people:

*In hospital you don’t know anything about them, you just see the patient in front of you… at home you see the person, you see dementia in the big picture…it’s about family as well. (P11, Phase 2)*

*They support each other, in hospital you don’t see and hear the personal side … it makes dementia more human […] you get to know about their life, family. (FG13, Phase 2)*

*Not to label the person with dementia. Nobody likes to be labelled. (P2, Phase 1)*

These findings are supported by extant research that suggests that contact with people living with dementia helps participants’ to adopt a person centred approach resulting in a more holistic view of the person (O’Reilly et al. 2012). Visits enabled participants to gain a glimpse into the subjective experiences of dementia, they described enhanced self-awareness and greater understanding of the person behind the label of dementia. Listening to a person with dementia and their carer seemed to promote person centred learning, prompting participants to see the person rather than their dementia, which, similar to Clarke et al’s (2003:698) study, enabled them to see behind the mask of ageing, illness or disability:

*Prior to visits… just heard the word dementia, but you will see dementia, you will observe dementia and you will feel…it’s more than a word, it’s like we’re going through
a journey, and, we are walking with them, they are going through a journey and we are walking with them…it’s a good feeling. (P8, Phase 2)

It’s not just seeing dementia as a case, you need to see person behind it [...] visits emphasised the importance of seeing the person and not focusing on their disability. (P1, Phase 2)

Before the program, I only know about dementia from my interactions in clinical placements, but after seeing them outside of a clinical setting in their own home, you see them as individuals. (P12, Phase 3)

It’s about looking beyond their dementia...making the best use of time to understand the person a bit more. (FG14, Phase 2)

Many of the participants were surprised by the abilities of the person with dementia, beginning to recognise the complexities of dementia:

In my head, dementia was a stereotype of they can’t remember things, but he’s very different...he keeps his mind active, you can see they have a quality of life even with dementia. He has only just stopped taking language classes...German I think. (P4, Phase 3)

Visits give (me) an individual perspective of dementia...when you read about it, it’s very focused on memory problems... whereas there’s obviously positive qualities to the person, for example, our guy, his sense of humour is just funny, he’s such a funny man and that wouldn’t come across if you just read about dementia. (P5, Phase 3)

Seeing the person with dementia from the perspective of social health led participants to focus on the person’s needs as advocated by Kitwood (1997); love, comfort, attachment, involvement and identity as demonstrated by the following examples:

Following our visits, I think more about the hospital environment... I feel like it’s definitely more important to communicate; sit down whilst they are having lunch and encourage them to eat and because I think to some extent they do get ignored which effects them and in a way that they can’t really express. I think more about how to support the person. (P9, Phase 1)

Participant 11 (Phase 1), summed up the changes in their perspectives of dementia:

...they’re real people...you know....I have more understanding of the experience of dementia... I need to adapt my approach to try to engage more with the person rather than just focus on their dementia.

These findings resonate with Kitwood’s (1997) concept of personhood and the NMC (2010:105) requirements that, nurses need to be self-aware and able to engage with people in their care. Findings demonstrated that participants gained a unique insight into the lived experiences of dementia from their visits. Participants’ identified that on busy wards in clinical practice, it was often difficult to see past the patient element, to see the individual person...
behind their dementia. This increasing awareness led to a person centred shift to all of the participants' practice, illustrated by examples shared which demonstrated a more humanistic approach to supporting people with dementia in their clinical practice.

Interacting with a person with dementia and their carer was described as ‘eye-opening’ by many of the participants, this was evident as I listened to them sharing their new perspectives on the world and they related more with the person with dementia and their carer. This was demonstrated by their recognition of the commonality of human experience that participants shared with older adults:

*Dementia does not just affect their health, it affects a person’s entire lifestyle – financially and socially.* (P8, Phase 2)

*It is life-changing…visits and interactions with person with dementia and family changed my perceptions of dementia and living with it in a positive way as you can live a normal life, I had not seen that side of it before…gave me insight and new way of seeing dementia.* (P12, Phase 2)

*They are just like you and me, they are trying to live their lives as best they can and make the most of their time together.* (P11, Phase 3)

Participants made frequent references to illumination and light throughout all three phases of the study to describe their experiences and changes of perception that resulted from listening to people with dementia and their carers.

*You will see dementia, you will observe dementia, and you will feel…it is more than a word, it was enlightening.* (P11, Phase 2)

*See dementia in a different light.* (P7, Phase 1)

Seeing people with dementia and their carers in a different light correlates with findings of Warne and McAndrew (2005) study which explored service users' involvement in education. During the process of coding I wrote in a memo:

*I have noted many references to light in relation to New Ways of Seeing; light seems to be a representation and reflection of what happened when participants experienced a connection with the person with dementia and their carer.*

Light seemed indicative of participants’ new understanding of dementia, which illustrated their *New Ways of Seeing* dementia as a result of *feeling connected* and being *present*. This led to increased recognition of the importance of *Building Relationships* with people with dementia and their carers. Buber (1965), used the image of light to describe the connections that are made in therapeutic relationships, proposing that it illustrates a sense of *wholeness* that occurs
through being more present in the context of a relationship, similar to the findings of the study. Listening to a person’s lived experiences of dementia engaged participants’ emotionally, this resulted in perceptions of dementia becoming more individualised, as participants’ assumptions and stereotypes were challenged. Findings from this study are similar to those of Surr et al. (2016) following a person centred training programme for hospital staff, both suggest that perceptions of dementia and feelings of caring efficacy towards people with dementia improved. Acknowledging the individual rather than focusing primarily on their dementia also resonates with the findings of Charter and Hughes (2012:584). They reported that healthcare practitioners also acknowledged the importance of seeing people with dementia as real people following training.

As the study progressed, it became apparent that many of the participants also began to make sense of what being a nurse meant to them. Participants from the study discussed feelings of hope in dementia as a result of their visits, this finding contrasts with the discourse of loss often associated with dementia, which some argue is a result of biomedical interpretations of dementia (Kitwood 1997; Sabat 2001; Smythe et al. 2014). Sacks (1985) calls this focus on deficits and neglecting a person’s remaining capabilities defectology, whilst Swaffer (2015), a person living with dementia, calls it prescribed disengagement. As Rolfe (2000:144) suggests:

> How we perceive an individual human being, health, and nursing’s work in our imagination literally makes a world of difference. Everything is totally interdependent and interrelated. Let us re-infuse the light of nursing with an open consciousness that acknowledges the uniqueness of each individual.

The next section discusses the conditions which were identified as the subcategories needed to establish the core category of New Ways of Seeing.

### 4.7 Conditions for New Ways of Seeing

During searches for common patterns during analysis of the interviews, focus group, reflective journals and memos, it became clear that New Ways of Seeing needed conditions in order to be established. As data collection and analysis progressed, three subcategories emerged from the constant comparative method in the data collected. These conditions are represented by the following three subcategories:

- 1: Adaptive Thinking
- 2: Building Relationships
- 3: Transformative Learning
These subcategories have been defined and confirmed over time, and although they are presented as discreet categories they are all interrelated as illustrated in Figure 9.

**Figure 9: Subcategories Related to *New Ways of Seeing*.**
4.8 **Sub Category 1: Adaptive Thinking**

**Figure 10: Components Related to Adaptive Thinking**

Throughout the 3 phases of the study, participants identified ways in which they had gained personally and professionally on their practice as a result of interactions during visits. There were frequent comments related to the development of skills and knowledge of dementia and examples of how this had informed their practice. Experiences seemed to enhance personal and professional growth of participants by challenging previous beliefs of dementia, their ability to understand the perspectives of the person with dementia and subsequently adapting their response. Participants shared many examples, throughout the three phases of the study to describe how they appeared to be moved towards action, rather than simply increasing their understanding of dementia as a result of their experiences.

Participant 3 (phase 1), discussed their feelings about dementia and the subsequent impact they had on her 'self' and her clinical practice following their visits:

*If I am being honest I didn’t want to do anything involving dementia and try to avoid it (in practice)…. I would actually say that I am more open and patient because before dementia would frustrate me. It opens you up to it all really hearing it from their perspective. I take more time to talk and listen in practice, I am more patient.*

Some participants were galvanised to action, demonstrating courage to speak out for patients, which is pertinent to their professional development; reporting a sense of preparedness for future clinical practice. They demonstrated advocacy skills for people with dementia and a
sense of professional awareness of what they observed as unprofessional behaviour. Participants shared many examples over the 3 phases of study, which demonstrated direct applications of their learning to practice demonstrating a move towards action rather than simply understanding dementia. These findings seem to support those of Grealish and Ranse (2009), who propose that students are more likely to seek alternatives when they have experienced an emotional connection. Participants addressing issues in practice is in keeping with the 6Cs (DH 2012), and the NMC (2015) duty of candour, which encourages healthcare practitioners to speak out against poor quality of care. Many participants commented that they felt that the experiences of their visits helped to develop their practice, sharing numerous examples throughout each phase which demonstrated action resulting from their experiences and listening to stories.

Wanting to make a difference in practice was a recurring theme throughout all 3 phases of the study. In phase 3, participant 2 discussed how she felt that the visits had impacted on her confidence and advocacy skills. She shared an example of action as a result of her experiences in the programme which demonstrated moral courage and principles of personhood in practice:

> I’ve seen other people in practice and I don’t always agree with how they treat people with dementia...they get cross, but shouting at people and getting cross doesn’t do anything does it? There’s been a couple of times I have stepped in – I am like, I’ll deal with this person. I feel confident...not to hold back.

This was echoed by another participant:

> Quite often I hear the care workers talking to them (people with dementia), as though they were five or four in a real childish babyish tone [...] they are not stupid. I hear that quite a lot and I think treating everybody as you would like to be treated [...]. As a nurse I want to try and make a difference. (P1, Phase 3)

Participant 9 discussed the impact of their visit experiences, compared to experiences and observations of dementia care during hospital practice placements:

> In the hospital environment I feel ... to some extent they do get ignored which affects them in a way that they can’t really express. I think more about how to support the person [...] as a result of my experiences of my visits, I engage much more [...] confident to try different approaches... to try and make a difference (P9, Phase 1)

Some participants identified how they felt that they got caught up in practice, focusing on the task in practice; reflecting that they did not make time to consider the person. Many discussed how they planned to incorporate lessons learned resulting from their visits into their own approaches, indicating action as a result of their learning experiences. Many participants
engaged in reflection about their position on the nature of dementia; inspiring review of their approaches to practice, demonstrated by participant 4 during phase 3 of the study:

My communication has developed, there’s nothing nicer than reading through ‘This is Me’ and making someone feel better and reassuring them...makes you feel good at the end of the day to make a difference...To be mindful of how they’re feeling, even if they can’t communicate, trying to spend more time to get to know the person [...] if I can bring that into my work, even if it’s five minutes of trying to find out what they did, that might help to build a relationship. Realisation that care is more than just doing task.

All of the participants’ discussed how much they valued the opportunity to practice their developing communication skills in a home environment that they felt was safe and non-threatening, with people who were willing to share their experiences. Recognition of the development of communication skills was discussed by participants in all 3 phases of study.

I felt a lot more comfortable and confident in practice with talking to people with dementia...changing my approach to support them. I feel much more confident talking about dementia and being with people with dementia in practice. (P8, Phase 2)

4.8.1 Being Challenged

Visits appeared to foster a broader understanding of dementia, changing perceptions, challenging assumptions, beliefs and stereotypes for all of the participants. Participant 12 summed up their experiences of the visits:

Programmes such as this illuminate the experience of dementia...talking about it helps to reduce stigma...gives an opportunity to slowly face our misconceptions and gives the next generation of healthcare professionals a better understanding of how to go about approaching dementia. Staff in practice often don’t know how to care for dementia, many just try and ignore it. (P12, Phase 3)

Many participants’ discussed their experiences of negative labelling, staff using negative language when talking about people with dementia whilst on acute hospital ward placements. This finding is consistent with the work of Beckett et al. (2007), who also identified that students often experienced nurses’ dismissive labelling of patients whilst in practice.

Nurses often label patients with dementia in care...they dismiss them [...] heard them being labelled as demented and blocking beds. [...] feel more confident to address labelling in practice. (P8, Phase 2)

People with dementia do not want to be labelled as that is not who they are. In practice people with dementia are often labelled as demented or referred to as ‘dementia patient’ or by their bed position rather than their name. [...] I always make a point of addressing the person especially during bedside handovers. (P2, phase 2)
All of the participants described experiencing powerful emotions elicited through listening to people with dementia and their carer:

Impact on me personally, you realise how precious life can be and how important relationships are...put things into perspective for me, made me appreciate life. (P1, Phase 2)

Seeing and hearing about dementia from the perspectives of someone with dementia appeared to challenge participants' assumptions and understanding of dementia, prompting many of the participants to consider their practice:

...have a better understanding of people who have it. It's like really bad to say but when I was in the hospital you can't really imagine these people before they had this condition. I think what it does is it makes them more human...visits gave me a better insight. After my visits I feel like hospitals the last place they should be, to some extent they get ignored. It has made me want to engage more in practice not just to focus on the task...I am more aware of dementia. (P9, Phase 2)

The experience has definitely changed my insight (of dementia), I am no longer afraid of it ...in hospital, people with dementia are often seen as really difficult and they are ignored... I have seen staff leave food on the table and move on to the next person because the person is too difficult to communicate with. I feel more confident in my communication skills, I sit down and take my time, communicate...take time and encourage them to eat their food by sitting with them. [...] it's the little things that can make such a difference [...] a smile. (P9, Phase 1)

Perceptions began to change as participants' understanding of dementia evolved to: seeing the person as being more than their dementia; seeing the person with dementia as a person, which resulted in participants' thinking and working in a more holistic way.

Participant 11 (phase 3), emphasised that they felt that educational interventions such as the Time for Dementia visits could:

Start to change perceptions of dementia for future healthcare professionals.

This finding is supported by Bradley et al. (2010), who proposes that education that reduces the fear of dementia may encourage students' to be more positive in their interactions with people with dementia. Findings from this study suggest that visits helped to positively impact on participants' understanding of dementia, which resulted in increased confidence in practice, demonstrated by participant 12:

It's a privilege to observe changes over time...interactions like this can start changing the perceptions of dementia [...] feel more confident, relaxed I suppose in caring and communicating with people with dementia (P12, Phase 2)
Later on in phase 3, participant 12 reiterated their perception that visits should be included in education of healthcare professionals:

_There should be less taboo about dementia. Programmes such as Time for Dementia as transformative, gives the opportunity to slowly face our misconceptions about it and give the new generation of healthcare professionals a better understanding of how to go about approaching dementia as a whole._

Some of the participants were open and honestly shared their feelings regarding how their interactions had inspired them to acknowledge and reflect on their perceptions of dementia, addressing personal biases as well as acknowledging the stereotypes of dementia that they held:

_If I am honest I didn’t want anything to do involving dementia and try to avoid it (in practice). I would actually say I am more open and patient because before dementia would frustrate me. Visits open you up to it all really, hearing about it from their perspective. I take more time to talk and listen in practice. (P3, Phase 1)_

One of the participants reflected on her experiences of the care of people with dementia in hospital and reflected on what care means to them as future practitioners:

_Dementia in hospital, focus is on doing. Care is very task driven, and you don’t know anything about them, you just see the patient in front of you…at home you see the person (P11, Phase 2)_

In phase 3, participant 11 shared her reflections on the impact that her experiences had on them:

_You start to think about it as not just the disease, you think about the person in general and I have more compassion as a result._

In some cases assumptions and stereotypes of dementia were based on participants’ prior experiences of dementia from working or volunteering in nursing homes. Following their visits participants spoke more positively in terms of hope, identifying that they could make a difference by focusing on the person rather than their dementia:

_I’ve had some terrible experiences in nursing homes, with violence…I felt drained at the end of the day after being punched, bitten…. Experience of visits and knowing there is a positive side to dementia, it’s not all negative…If I hadn’t seen it I wouldn’t have believed there was a positive to dementia. My first couple were the ones that made me realise the importance of using ‘This is Me’, now I always get families to fill them out in practice if they have not done one, it’s really useful in planning care – simple things like “my mother doesn’t like cheese” really makes a difference… holistic care that focuses on the person. (P4, Phase 3)_
Later in her interview, participant 4 shared an example of how her experiences had impacted on her practice:

*I think I've learned not to be so afraid of it (dementia)… definitely feel more confident in practice. I am not afraid to try different approaches in care, to be more present in my practice.* (P4, Phase 3)

These findings reflect the views of Rudman (1996), who advocates that a non-judgemental approach towards people with dementia, thereby acknowledging people’s experiences and considers the reasons behind behaviour rather than making a judgement. Participants shared numerous examples of how they felt their increased insight of dementia impacted on their practice and focus on the person more rather than just their dementia diagnosis:

*I now spend more time (in practice) to try to get to know the person…trying to find out what is important to them, to help me to build a relationship with them. [...] see the person behind the label of dementia.* (P2, Phase 3)

*Developed my confidence…I’m able to approach people with dementia in a different way and try different approaches.* (P12, Phase 2)

During phase 2 interviews, participant 7 shared her reflection regarding the care of a person with dementia she had been involved with during a practice placement prior to her visits as she reflected the unique contribution of the visits:

*In clinical placements before my visits we had a patient with dementia who was very angry and nobody stopped to work out why...he was incredibly frustrated. Now that I’ve been on my visits I reflected on what we could have done differently. I would spend more time trying to get to know him, approach him differently. The outcome could have been different and we could have made a difference* (P7, Phase 2)

Many participants discussed putting themselves in the shoes of the person with dementia and their carer; resulting from their attempts to try and understand how they may feel regarding the changes they were observing. de Waal (2008) suggests that viewing others’ emotional state may lead to state matching as the person starts to associate personally with the other person, which he argues is integral to the developing of deeper levels of empathy. Some of the participants’ discussed how they felt that the experiences of their visits led to:

*A greater ability to be empathetic with others, [...] being able to step into their shoes* (P1, Phase 3).

*Picture myself in his shoes (person with dementia), [...] I try to imagine how the person may be feeling more when I am in practice.* (P7, Phase 1)
Experience has changed my perception (of dementia)… gave me more of a personal view…seeing it from their shoes, through their eyes […] feel more empathy as a result. (P6, Phase 2)

For many of the participants, service user and carer involvement appeared to be effective in breaking down boundaries as perceptions of dementia were challenged, normalising and humanising dementia.

Participant 2 described their experiences of being given the opportunity to enable them to see dementia through the eyes of a person with dementia as life changing, they had no personal or professional experience of dementia prior to their visits, reflecting that the personal view can help to challenge stereotypes.

These findings are consistent with Unwin, Rooney and Cole’s (2017) study which also reported that perceptions changed from seeing service users as stereotyped others to seeing them as fellow human beings. Although service users in their study had disabilities, which did not include dementia, findings were similar to findings of this study, as perceptions of students were challenged.

Participant 8 (Phase 2), summed the impact of her visits:

Prior to visits, just heard the word dementia but (visits), you will see dementia, you will observe dementia and you will feel dementia. It’s more than just a word.

4.8.2 Seeing Hope

Through engagement and listening, rather than focusing on their disabilities participants seemed to be awakened to the continued abilities of people with dementia, which seemed to result in a shift in their personal understanding. Participants spoke about hope and living which seemed to be surprising for them in dementia.

I see lots of hope…I didn’t expect to see hope in dementia. […] seeing how they are coping. (P12, Phase 2)

They’re still enjoying life, still going out….I didn’t expect that…seeing hope in their lives…I thought that they will not enjoy a good quality of life. (P11, Phase 2)

Interactions seem to have challenged participants’ assumptions of what dementia is and, as a result, seemed to have moved them beyond negative stereotypes of dementia. Gaining insight and seeing people in a new light caused many to reflect on their role in caring for people with dementia, resulting in a motivation to want to make a difference:
Knowing there is a positive side to dementia, it's not all negative...I don't think if I hadn't have seen it I would have believed that there was a positive to dementia...there is hope in dementia. You can make a difference. (P4, Phase 1)

I wrote in my memo during phase 1:

Participant 4 discussed as early as phase 1 that she felt her experiences of her visits; will 100 percent always stick with me you know. This was poignant as she later shared how she felt most of her clinical experiences of working in care homes and ward placements had been negative, however she seemed to shift her understanding of dementia to be awakened to existing abilities rather than focusing on disabilities:

Visits seem to highlight the daily practice of living with dementia and the ways that people can keep life enjoyable. Findings suggest that there is so much we can learn by bringing the conversation back to people living with dementia to emphasise that they are so much more than their dementia:

Seeing someone in their own home, how well a person can live with dementia. I have only ever seen people who are acutely unwell. She was doing one language, he (person with dementia) was doing another! It has been very valuable for me listening to them tell us about their lives and how they are making the most of living. (P4, Phase 1)

4.8.3 New Insights: Carer

Visiting people with dementia and their carers enabled participants to recognise and explore the significance of relationships in relation to supporting a person with dementia to adapt and cope. All of the participants recognised the vital role of the carer; describing the supportive roles they play in the lives of the person with dementia. Reflecting the biopsychosocial approach of seeing the person with dementia and their carer, participants had an opportunity to see and hear about their relationships from a holistic perspective. Adams and Gardner (2005) and Molyneaux et al. (2011) suggest that relationship-centred care may be a more beneficial term to use than person centred care to recognise the importance of couplehood in dementia. It was apparent that there was an increased understanding of the importance of the carer relationship and how crucial it can be to enabling the person to live well with dementia:

She (wife) does that beautiful...life story book...she did take him to Scotland when they could travel and she took pictures of where they went to school and she sorted out pictures of his family...it was really lovely because it gave them lovely memories to share together...it was a privilege to share as well. (P10, Phase 1)

Seeing how well a person can live at home with dementia. I have never seen that side of it...experience has made me appreciate the importance of relationships in dementia. (P4, Phase 2)

I think we learnt a lot about their life experiences not just in terms of dementia aspect but everything else like what they do these days and how they cope with it and what
they used to do before and the conversations they used to have before like for example her husband was saying I would ask my wife “what will you do if something were to happen to me or what would I do if something were to happen to you?” so we definitely saw some coping mechanisms that they had beforehand and they still have now. (P9, Phase 1)

I wrote in a memo during phase 2 of the study:

Listening to the students reminded me of reading the work of Christine Bryden, she talks about her husband as an enabler rather than a carer which seems an apt description of many husbands and wives supporting their spouse with dementia and reflects what participants are seeing on their visits.

A few participants described empathetic responses as a result of listening and observing relationships during their visits.

Listening to them, it was so emotional…I guess it is the realisation that things will never be the same again. (P2, Phase 1)

Some participants discussed how they felt that the visits had increased their awareness of some of the concerns of carers regarding the future which they had not considered prior to the experience of their visits:

She was very worried, him [person with dementia] outliving her, I never thought about that side of things before…eye opening. (P3, Phase 1)

She worried about fire, I hadn’t thought about things like that because in the hospital it is a controlled environment, at home it is different […] more aware of the need to talk to carers before discharge to ask if they have worries. (P10, Phase 1)

Participant 5 shared experiences she had in practice of carers being labelled, viewed as blocking in relation to discharge. As a result of her visits, she gained new insights and perspectives in relation to the role of carer, which impacted on her practice.

I don’t think a lot of the time the carer is taken into consideration. From my experience a lot of the time, it’s like great someone’s carer, perfect, they can go straight away then. There is no package of care to put in place… out you go. Rushed; one day they are here and the next day you phone… and say, he is coming home today come and pick him up.. Actually seeing that now from the other side, that must be impossible and emotionally…I now consider the carer much more when looking at planning discharge. (P4, Phase 1)

Many of the participants shared examples of changes they had made to their practice towards carers as a result of their experiences:

When I am on placement, I now make sure that I ask carers’ how are you and engage with them more. Before my visits I did not really consider their needs. (P2, Phase 2)
I encourage carers to fill out This is Me to help us in our care […] it is really important to work in partnership with them in practice. (P10, Phase 1)

In placements I do feel much more confident in approaching carers and asking them “how are you?” I try to engage carer much more […] made me reflect on my practice after she shared with us how they felt ignored by healthcare practitioners and how it makes a huge difference if someone asks how are you doing? Before my visits I did not really consider their needs. (P10, Phase 2).

4.8.4 Maintaining Couplehood

Some participants perceived that some carers did not identify themselves as carers; they described themselves as a partner/husband/wife within their relationships, many of the participants observed that in practice the term carer is frequently used.

They’ve got a very loving and caring relationship…over time I can certainly feel there is love between them, even as the dementia progresses that remains, you can see and hear it. They still see themselves as husband and wife. (P8, Phase 2)

Unique opportunity to see people with dementia and their carer in their own homes over time to see how they change and adapt to those changes. It was interesting to see the family unit and how it changed and how they were making it work together. (P12, Phase 2)

In practice I try to avoid using the term carer unless the person themselves uses it. I learnt from my visits that she hated being called a carer by healthcare professionals, she was adamant that she was not a carer, she was his wife. (P2, Phase 3)

These findings are similar to Molyneaux, Butchard and Simpson's (2011) study of couples, which explored the impact of dementia on couplehood. They also found that many husbands and wives did not see themselves as ‘carers’: Participants' in this study shared their observations that couplehood seemed to be maintained by preserving social networks as much as possible. This finding is supported by Robinson, Clare and Evans (2005) study of couplehood following the onset of dementia, they also reported that hope and relationships was maintained by focusing on the positive aspects of their lives such as maintaining social networks.

Their relationship, even though he is deteriorating…you can tell they’re obviously very, very close. They reminisce a lot about holidays…you can tell they’re very much in love…they rely on each other a lot…They still go out with friends and maintain a good social life. (P1, Phase 2)

Participants discussed some of the strategies that they had observed that carers used to support their spouses:
She had lots of pictures everywhere to help jog his memory…she’s still trying to get him out and engage socially…singing for the brain which he really enjoyed. (P1, Phase 1)

…she has to remind herself not to remove all the control from him and if he wants to control how his clothes are laid out on the bed then he needs four pairs of pyjamas – that is fine that doesn’t matter. …you know he clearly is very comfortable and she provides a brilliant environment for him. (P10, Phase 2)

One of the participants shared how they felt that the visits provided an opportunity to have a break from their normal routine, giving the couple time to talk:

Some of the things that they have said, they’ve never actually verbally told each other, and it was such a privilege for us to actually come in and facilitate the opportunity for them to discuss it in a health way, and their appreciation for each other, like a couple thanking each other but never had the chance. […] privilege to be part of. (P12, Phase 3)

4.8.5 Perceptions of Loss

Although participants discussed positive experiences they had observed, they also recognised the profound impact dementia had on the carer, especially on those who perceived a change of role from husband/wife to carer as highlighted by O’Connor (2007) and Vernooij-Dassen et al. (2006). Participants discussed their perceptions of the changes they observed over time within family relationships; their perceptions of a shift in relationships with some partners beginning to see and talk about themselves as carers in the relationship rather than the relational role they had previously. These findings are similar to studies of carers of people with dementia by Vernooij-Dassen et al. (2006); Hellstrom, Nolan and Lundh (2007) and O’Connor (2007). Some of the participants reflected on the impact in terms of loss:

Sense of loss…hearing it from her and seeing her looking into my eyes and with her being so honest…. I don’t think you get that in a classroom – massive part of learning (P5, Phase 1)

He is not necessarily her husband anymore, the dynamics have completely changed …felt real sense of sadness…and loss. (P4, Phase 1)

…wife and husband relationship was no longer… it was a caring relationship which was sad …She said she didn’t feel like his wife anymore…sad to hear. (P3, Phase 1)

The longitudinal nature of the visits enabled participants to travel some of the dementia journey with the person and their carer which helped them to gain an appreciation and insight into changes over time. Many of the participants shared their observations of relationship changes observed over time:
I think she sees herself as more as his wife again rather than a carer, because they’ve got the help...originally (first 2 years of visits) she was like, “No I don’t want anyone coming to the house, he wouldn’t like it, but actually he’s got a really good relationship with his carer.” She seemed so much more relaxed and happier. (P2, phase 3)

It’s gaining awareness of the differences in the roles of people, the couple we visit have disclosed that it has affected their relationship. There are role shifts, privilege to actually see and hear changes over time…valuable and unique. (P12, phase 3)

Some of the participants spoke of a sense of anger and frustration that carers shared with them:

She (wife) said now that she has accepted that she is a carer for him and we spoke about the dynamics about how that relationship has changed. That was really interesting to talk to her… She doesn’t appear to get anything from the relationship she said now that she think it is all giving, you know it is all giving… the actual relationship it is all very one sided….she (the wife) said he remembered the cat but he won’t remember her. …She says she does gets frustrated with him and then she says she feels guilty because she gets frustrated (P10, Phase 1)

…she was quite angry at the situation of having to go from the wife to the carer. (P6, Phase 1)

Only one of the relationships involved a son and mother relationship, participant 7 wrote in her journal entry her observations of changes in roles in their relationship:

Son was negative as he had to take on role of carer for his mother. The impact that this had on his relationship with his mother is that that it seems to have become his ‘job role’ rather than visiting her for pleasure. This observation made me feel sad.

4.8.6 Learning about Oneself

One of the advantages of the sequential visits over 3 years is that it seemed to encourage participants to reflect on their changing perspectives of themselves and their role as a nurse in caring. Significant learning can occur in what Piaget (1985) terms cognitive disequilibrium whereby students are forced to step outside themselves when faced with and encountering new or unfamiliar experiences to reflect critically on their attitude and feelings. Piaget (1985) and Kegan (2000) suggest that the self-reflection that can result from this fosters personal growth and development.

We are learning quite a lot as a person, not only as a student […] experience has been transformative. (P6, Phase 3).

The following comments demonstrates a growing awareness of professional identity by some of the participants. Visits seemed to encourage participants to adopt the perspectives of people with dementia, motivating them to reflect on their practice and their development as nurses:
Whole experience has made me consider what kind of nurse I want to be. (P8, Phase 1)

See visits as helping to aid me develop as a caring nurse...importance of seeing and working with the whole person...whole sight I suppose [...] my confidence and my attitude has changed dramatically with dementia patients....you don't mean to but you play ignorant because you don't really know, the more you do know and the more you're exposed to it you just have more time and understanding...my perception of dementia has changed for the better. I am not afraid to of dementia. (P7, Phase 2)

Later in phase 3, participant 7 discussed their feelings of increased empathy as a result of their experiences:

Definitely feel that I am more empathetic towards people with dementia and their carers. I try to find out more about them to try and help support them in the best way I can. (P7, Phase 3)

This was reflected by participant 11 (phase 3) who discussed how:

As a result [of visits], you think about the person in general [...] , their whole lives and their relationships and I have more compassion as a result.

Many participants identified that they needed to move away from focusing on completing tasks to give priority to understanding a person’s experiences, planning and providing care that enables and affirms the person. The emotional impact of listening to the person with dementia and their carers seemed to motivate the participants to consider how they wanted to develop as nurses. Participants seemed to grow in self-confidence, acknowledging the importance of being with, listening and feeling comfortable with silence:

I have learned the importance of the nurse’s role in just being with...just listening and feeling comfortable with silence (P5, Phase 2)

Time for Dementia has taught me that listening is so important...it helps you to care for the person...not focus so much on the doing but being...visits help us to build relationships...see the patient as holistic and think more about how to do nursing care in that way in placements (P8, Phase 2)

In phase 3, participant 8 shared an example of the impact of her experiences on her practice:

I really understand what it means to listen and to be more sensitive to the needs of the person.

Participant 2 had no experience of dementia prior to her visits and summed up her experiences as life changing:

Gave me much more of a personal view...I don't really know anyone with dementia; listening to them talking about their experiences...what they first noticed, how their lives changed, has given me a lot more of a personal angle to it...seeing it through their eyes
and personal journey. Life changing seeing dementia through their journey. Helped me to link theory and practice. (P2, Phase 1)

4.8.7 Uniform and Identity

Uniforms emerged as a powerful image during phase 1 of the study. Wearing uniform seemed integral to identity and professional image for some of the participants. The frequency of references to uniform led me to explore the literature around uniform and nursing and add it as an interview prompt in phase 2 facilitating further exploration. Although uniform in nursing is familiar and can symbolise status and group identity, I wrote in my memo that I was surprised that participants identified with uniform so early in their education (phase 1). I also questioned how wearing uniforms fitted with government’s emphasis on liberating the NHS from tradition and bureaucracy (DH 2010a). Some of the participants spoke about the impact of wearing their uniform in terms of helping them to prepare for ‘playing a different role’ to their ‘normal self’. During this phase I wrote in my memo:

A few of the students have talked about how they feel different when they wear their uniform – they appear to be a powerful image for them in terms of having authority when wearing. I sense that putting on uniforms becomes part of their professional persona and it may be used to keep some distance from patients. I sensed that they may be using their uniform almost like an emotional boundary to protect themselves from getting too involved. In contrast – some of the students feel more freedom not wearing their uniform during their visits. I will need to use more probing questions in the next phase of interviews to try and get a better understanding to enable me to explore what they are experiencing and feeling.

Participant 6 (phase 1), discussed how not wearing a uniform emphasised the importance of being with and engaging rather than doing tasks:

I think that not wearing uniform helped us to engage and I think it helped them to engage with us... if I wore my uniform I would be thinking of doing assessments rather than spending time getting to know them. Helped me to step back. Focus on being with rather than thinking, “what I need to do next?”

I noted that a few of the participants seemed to struggle with not wearing their uniform, especially in the beginning of their visits. During phase 2, participant 3 discussed how: they feel more comfortable wearing uniform...because it (uniform) is like a boundary. When asked to expand on this she discussed her feelings of wearing uniform in terms of protection and not getting too involved:

My worry would be that the carer would become a bit attached to us...I empathise with her because I feel sorry for her but I don’t want to become too attached because then you will get emotional about it or something.(P3, Phase 1)
This finding resonates with the seminal work of Menzies (1960), she posits that nurses often distance themselves from patients as a defence against the anxiety caused by caring. Dowling (2002) suggests that whilst nurses are expected to care with empathy, they are also encouraged to maintain a degree of emotional detachment in what she termed as a *safe equilibrium*. It was interesting that many of the participants expressed how they felt that wearing uniforms helped them to psychologically prepare for their placements.

*When I have my uniform on I am very different. I think with a very different head you know. I act very differently.* (P7, Phase 1)

*I feel like it’s almost a sense of when you put your uniform on you change persona... It felt very personal (not wearing uniform), it didn’t feel like a professional relationship it felt very personal to me and you know she was going to look out some old pictures and stuff and it was nice because it broke down that professional boundary that you build up when you have the uniform on but it was also quite uncomfortable at the start (laughs)* (P6, Phase 1)

*I think you put on a professional front when you have your uniform on...differentiates me from (name) at home and (name) the student nurse. As soon as I take the uniform off my day is done and when the uniform goes on I’m in professional mode again.* (P4, Phase 3)

Some of the participants identified that not wearing uniforms helped them to develop their partnerships and engage more with the person during their visits:

*It helped us to engage and I think it helped them to engage with us* (P6, Phase 1)

*I feel proud to wear my uniform...but without my uniform, yeah, like you feel you can ask question freely, I feel more relaxed. [...] I think it helped them to relax with u as well.* (P11, Phase 1)

Not wearing uniform seemed to help reinforce the mutuality of their visits for some participants:

*They are not patients they are participants with us and we’re learning from them* (P12, Phase 2)

*You’re on the same level...I feel like I’m going in as myself rather than my student self.* (P2, Phase 2)

### 4.8.8 **Summary: Adaptive Thinking**

Growing awareness of observing the abilities of the person with dementia rather than their disabilities, appeared to challenge all of the participants’ preconceptions and stereotypes resulting in focusing on the person. These findings were similar to those of Schneebeli et al.
(2010) and Thomson and Hilton (2011), who also reported that visits appeared to benefit student learning about dementia, challenging assumptions and stereotypes. Instead of viewing people with dementia as a homogenous group, participants’ began to see the person as an individual rather than just their dementia. Gerritsen, Oyebode and Gove (2016:6) propose that if health care professionals perceive people with dementia as a homogenous group, a group-based approach to care may be fostered, which they argue increases the risk care provision that is task-based. This notion of homogeneity has similarities to Tappen et al’s. (1999:124), earlier work suggesting that a lack of awareness of appreciation of personhood can often lead to task-orientated care as a result of low expectations of therapeutic potential with people with dementia. Findings of this study suggest that spending time and having an opportunity to develop relationships with older adults with dementia and their carers helped to dispel many of the stereotypes of dementia. As explored in Chapter 2, evidence suggests that negative attitudes of nursing students are often based on myths and stereotypes about people with dementia. As Celik et al. (2010:25) emphasises:

Today’s students are tomorrow’s health care professionals, the development and cultivation of positive attitudes towards ageing and older people is crucial.

Many of the participants reflected on, during their interviews and journals, how their visits contrasted with their clinical placement experiences. Repeated and regular contact seemed to engage participants to listen, enabling them to understand the importance of the personal context of dementia, consequently this seemed to encourage them to explore the embodied experiences of dementia. These findings contrast with the medical model of dementia, which Cottrell and Schulz (1993) suggests, often positions the person with dementia as objects of their illness rather than participants in care. Smythe et al. (2014) suggests, this focus may lead to negative attributions being made by staff working in acute care towards people with dementia; as the challenges associated with dementia are seen as being their fault. Seeing behaviour(s) as deliberately challenging may lead to what Weiner (1985) calls attributional theory, as negative attributions towards the person with dementia may lead staff to fail to address the support that the person needs.

Findings of this study seem to contradict Barker (2004:18) assertion, that having a diagnosis in mind when listening to a life story can obscure rather than illuminate the person’s story; resulting in objectifying the person into a type of pathology. In contrast, findings from this study suggest that as a result of visiting people with dementia, participants’ spoke of New Ways of Seeing, prompting them to focus on the person rather than their dementia. Keady and Gilliard (2002) propose that if healthcare professionals focus on loss in dementia it is threatening to
the person with dementia’s sense of self. Both Kitwood (1997) and Sabat (2001) assert that people with dementia react to how they are treated, which impacts on their quality of life.

It was apparent that as a result of visits, participants’ had an increased understanding of the importance of the carer relationship and how crucial it can be to enabling a person to live well with dementia. Findings suggest participants had greater awareness of the impact of dementia on carers and time spent caring, fostering relationships reinforcing the importance of family relationships in dementia. This finding is important as other studies report that family carers often criticise that their contributions are not recognised by healthcare professionals (Dewing and Dijk 2016; CBunn 2012). Bowers (1988) suggests that if healthcare professionals foster relationships with families, it can help families to maintain a sense of involvement and self-worth. Therefore it is essential that nursing students understand the importance of these relationships and their complexities to enable them to see the person with dementia from a holistic perspective, which supports a biopsychosocial framework of dementia. Liaschenko (1997) propose that person knowledge is essential to promote and maintain individual integrity, however, the development of this knowledge takes time. Participants recognised that the longitudinal visits provided time and opportunity for them to develop and foster relationships which helped them to connect with a person with dementia and their carer over 3 years.

As previously discussed, throughout the interviews and journal entries, participants’ made frequent references to New Ways of Seeing dementia, which resulted in the person with dementia becoming more than their dementia. As Sabat (2001) observed, language is a powerful tool with words reflecting our thoughts and feelings; frequent references were made by the participants, within each phase of the study to, humanise and empathise. As Howe (2013) contends, being able to humanise and empathise with patients are essential in developing successful personal and working relationships in caring professions. Findings suggest that visits promoted self-exploration, demonstrated by participants’ exploring their own values, resulting in increased self-awareness of themselves and what being a nurse meant to them. Many of the participants seemed to have undergone changes as self-exploration resulted in adaptive thinking about dementia, which led to changes in their practice. This is consistent with Carpenter (2010) and Byrne et al. (2013) findings, who proposed that when new insights are gained, students are encouraged to look at their own approach to care provision and new ways of working. Participants discussed examples of action as a result of their experiences, sharing examples that demonstrated moral courage to step in and not confirm to outdated practices, acting in a manner consistent with their values. Through their empathetic learning, participants appeared motivated to advocate for people with dementia, demonstrating
confidence to challenge care which, as Benner (1984) asserts, takes the student from detached observer to individual performer. Participants spoke about how they felt that their interactions had positively impacted on their confidence especially in communication, this knowledge appeared to give them the confidence to try different approaches in practice which was reflected in numerous examples shared over the three phases of data collection. These findings contradict previous literature findings, which suggest that nursing students often lack the moral courage to intervene (Bickhoff et al. 2016). The scoping review of service user involvement in nurse education in Chapter 2, identified that despite reviewed studies articulating that students’ learned from their experiences of service user involvement, there was no evidence of action or reflection reported (Christiansen 2011; Gidman 2013).

Analysis of the data suggests that participants’ experiences of the visits enabled them to develop skills in moral perception, an element of ethical competence (Gallagher 2006), which Iris Murdoch (1970:33) referred to as attention which can:

...express the idea of a just and loving gaze directed upon an individual reality. I believe this to be the characteristic and proper mark of the active moral agent.

Murdoch’s idea that by paying attention properly, one comes to see what must be done arguing that:

I can only choose within the world I can see, in the moral sense of ‘see’ which implies that clear vision is a result of moral imagination and moral effort. (Murdock 1970:37)

Simons et al. (2007), suggests that in clinical placement students focus on the immediate task and clinical issues presented by service users rather than focusing on the person. Hall and Hoy (2011), also identified that although nurses expressed a desire to provide individualised nursing care, they often followed routine and protocols focusing on physical care. They propose that this may result in nursing students adopting negative practices; which Berntsen and Bjork (2010:18) term as adopting: the most effective way of acting learned so far; suggesting that these negative practices may be carried through their nursing career. Similarly Curry et al. (2001) suggests that the delivery of individualised care is impeded by traditional nursing cultures that focus on the task and does not recognise the uniqueness of the person. In contrast, findings from this study suggest that interacting with people with dementia in their own homes enabled students to see beyond their clinical issues, gaining insight into the wider context of the resulting impact of dementia on a person as well as their carers. All of the participants’ discussed the need to move away from focusing on doing and completing tasks, instead they spoke of the need to prioritise understanding a person’s experiences; planning
and providing care that enables and affirms the person, all of which correlates with Kitwood’s concept of person centred care (1997). Participants made frequent references throughout the study to focusing less on the task and more on providing care that focused on the person. Frank (1991), differentiates care from treatment, arguing that treatment is a technical routing, whilst care is what is communicated by words and actions, demonstrating understanding and empathetic concern for patients. Participants demonstrated care as described by Frank (1991) throughout the study. The impact of service user involvement resulting in reports of increased holistic and person centred care in practice are similar to other studies in mental health education (Morgan and Jones 2009; Terry 2012; Rhodes 2012; Perry et al. 2013).

Findings appear to demonstrate participants’ personal and professional growth by challenging their beliefs of dementia, thereby enhancing their ability to understand the perspectives of people with dementia. These findings resonate with Allport’s (1954) contact hypothesis theory, whereby contact helped to reduce prejudice when opportunities such as visits are present for actively taking the perspective of another person and considering the situation from their viewpoint. Aronson (2000) Pettigrew and Tropp (2008) and Skorinko and Sinclair (2013), concur with this adding that taking the perspective of an older person can decrease stereotyping. Similar to findings of this study, their participants’ also demonstrated perspective taking throughout their visits, discussing how they could imagine themselves in their shoes and seeing dementia through their eyes. Galinsky, Ku and Wang (2005) define perspective taking as the process of individual’s imagining other perspective from another’s vantage point or imagining oneself in another’s shoes reflecting the experience of many of the participants in this study. Visits led to increased awareness of dementia, demonstrating how listening to people with dementia and their carers can make a contribution to personal development by challenging assumptions of dementia. Findings are supported by previous studies by Schneebeli et al. (2010) and Thomson and Hilton (2012), who also reported that service user involvement encourages assumptions and stereotypes to be challenged. Many of the participants’ described the ideal of treating patients the way that they would like their family to be treated, consequently some participants discussed the impact of observing poor practice quite personally. Findings suggest that participants developed feeling strong emotional connections with people with dementia, enabling them to see the situation from the perspectives of people with dementia and their carer, which may have contributed to their confidence in speaking up in practice.

Scott (1997) suggests that nursing students are predominantly educated on the clinical features of disease, arguing that as a result students often focus on physical complaints which
can result in dehumanising effects which are harmful to the patient. She advocates that failure to see the patient as a person fails to respect their rights and human dignity and results from a lack of empathy. Furthermore, she proposes that students cannot empathise with a person if they cannot imaginatively enter their world and identify with them. Findings from this study suggest that participants were able to enter the world and adopt the perspectives of a person with dementia. Participants seemed motivated to reflect on their practice and their development as adult nurses, which was demonstrated by the frequent references made throughout the study of: new ways of seeing and seeing it through their eyes. This resulted in changes to participants’ approaches in their practice, demonstrated by numerous examples of a more empathetic approach to supporting people with dementia and their carers. Fagermoen (1997:435) defined professional identity as: the values and beliefs held by the nurse that guide her/his thinking, actions and interaction with the patient. The emotional impact of listening to a person with dementia and their carer seemed to motivate many of the participants to consider how they wanted to develop as adult nurses; they expressed how much they learnt as a result of their visits and more importantly demonstrated how they incorporated their learning into their care.

Uniforms emerged as a powerful image during analysis of the first phase (phase 1) of the study; many participants seemed to view their uniform as integral to their identity as a nurse. Kerry (1996) and Joseph and Alex (1972), propose that uniforms are an important emblem of group membership and can help some nurses to define themselves. This view is supported by Sparrow (1991) study of one hospital ward where staff did not wear uniforms for two months. She identified that staff felt that uniform was an important part of their identity as nurses and distinguished them from other groups and contributed to their confidence. Findings of this study are similar to Shaw’s (2010) study of nursing students, which also found that wearing a uniform increased their confidence, reporting that it helped them to psychologically prepare for work. Although Shaw’s conclusions were limited, due to the size of the study (n=14), findings highlighted that for many of the students uniform appeared to play an important role in forming their professional identity and maintaining their pride in the profession. Conversely a more recent study by Keeling and Templeman (2013:21), which explored student nurses’ perceptions of professionalism, did not identify that uniform was perceived by them as helping to form their professional identity.

Although some participants in this study expressed feelings of anxiety about not wearing uniforms for the visits, many felt that not wearing uniforms during their visits helped them to engage more as they could be themselves. Over time, some participants reflected that they
felt that wearing a uniform may have been seen as a barrier, identifying that not wearing it seemed to help the person with dementia and carer engage with them more. This finding is supported by Sparrow (1991:120), who also identified that when nurses were not wearing uniforms, roles appeared less defined and they were seen as more approachable by patients. This resonates with Brennan et al. (1995:36), who reported that that 83 per cent of patients felt that not wearing uniform took away the, *them and us* effect; 77 per cent of patients identified that it made them feel more equal. Within the practice of dementia care, the appropriateness of wearing uniforms, especially in the care home industry, is often debated in relation to supporting the delivery of person centred care. Many dementia experts advocate that staff should wear their own clothes, proposing uniforms can create a barrier and people living with dementia sustain higher levels of wellbeing if staff wear their own clothes (Cohen-Mansfield 2005; Sheard 2008; Charras and Gzil 2011; Ericsson, Kjellstrom and Hellstrom, 2011). They advocate that not wearing uniform is supportive of a person centred culture where the person really is at the heart of care.

The NMC (2010) assert that practice placements appear to be the primary way nursing students are socialised into the nursing profession, arguing that its influence should not be underestimated on their development. This view is supported by critics who suggest that negative experiences in placement can impact on students not wanting to work with older people and people with dementia (McCann et al. 2010; Stevens 2011). Findings from this study suggest that experiences during visits contrasted with participants’ experiences of dementia in clinical practice. Some participants shared their observations of labelling people with dementia and patients being seen as difficult:

*In practice, nurses often label patients with dementia in care…they dismiss them […] heard them being labelled as demented….being ignored.* (P8, Phase 2)

Beckett et al. (2007), also found in their study that nursing students reported hearing dismissive labelling of service users in practice placements, especially those who were viewed by nurses as having complex needs.

Nursing curricula needs to reflect the changing landscape of the *workplace* and innovate to enable students to understand the contexts of the lives of people with dementia. It is essential therefore to design dementia nursing curricula that is proactive rather than reactive to ensure that it directs and informs the future nursing profession. Visits appeared to promote new ways of working as well as *new ways of seeing* dementia, which resonates with Frank’s (2010) assertion that stories can incite reflection, leading to personal as well as professional
development. Findings suggest that new insights into dementia, led participants to focus less on their drive to do (tasks), to recognise the importance of being with the person (presencing) and building relationships (Figure 11). It could be argued that if attention is only given to doing skills, the uniqueness of the person with dementia may be lost, consequently lessening participants’ ability to be present and build relationships.

4.9 Sub Category 2: Building Relationships

Figure 11: Components Related to Building Relationships

4.9.1 Being Present

Recognising the importance of being present was discussed by all of participants. Participant 12 spoke about feeling more present in her practice as a result of her visits; sharing the resulting impact this had on her care provision:

*I'm more prepared to dig deeper in my next placement should I encounter someone with dementia, I'm able to approach it in a different way and feel more confident to try different approaches…be more present I suppose in my practice. (P12, Phase 2).

Participant 8 (phase 3), also spoke about being present and the resulting impact of being more sensitive in their practice:
Feel more about their problems….understand what it means to listen and to be more sensitive to the needs of the person with dementia…to be more present I suppose….

This was echoed by another participant:

*I have learned the importance of the nurse’s role in just being with (presence)…just listening and feeling comfortable with silence.* (P5, Phase 3)

Reflecting on their approaches to care when in practice; participants gave powerful examples of being present and how they focused more on being with patients rather than doing for which is similar to the work of both Strickland (1996) and Hanson and Taylor (2000).

*We do things (in practice), we don’t take time to listen to the patient with all the medical side, it’s the quick fix - we don’t really take time to pay attention…I now spend more time listening and getting to know the person and their carer in practice.* (P8, Phase 1)

Some of the participants came to the realisation that there may not be a nursing solution; realising that their role involved not always finding solutions and instead making a commitment to ensure that the focus of nursing care remains on the person as demonstrated by the quote below:

*Biggest impact for me has been the realisation…sometimes people do not want answers, they just want people who will listen…realisation of how important human interaction is.* (P1, Phase 2)

This was also reflected upon by another participant:

*There is no quick fix….there is no cure; nursing care is about supporting the person to try and improve the quality of their life and living.* (P8, Phase 2)

Participants described how they felt they had gained a better understanding of what life was like living with dementia, especially as their relationships developed over time. Longitudinal visits provided adult nursing students with an opportunity to enrich their understanding of dementia, which seemed to foster a more humanistic perspective of dementia. This recognition was demonstrated in a shift in participants’ approaches to their practice demonstrated by many examples of a more humanistic approach to supporting people with dementia in their clinical practice.

*I feel I have increased empathy as a result (visits)* (P1, Phase 1)

Participant 1 (phase 3), went on to discuss how she valued being able to *share their journey* over time and shared an example of the resulting impact that the visits had on her practice as she showed humanistic concern for a carer:
I had a patient with dementia in a palliative care setting....I took his wife aside and had a chat with her. I’d said to her like, go home and get yourself some sleep because you’re absolutely exhausted, and then I gave her a ring later just kind of reassure her. You have to kind of remind yourself we’re all human and they’ve been together for 60 some years, had never spent a night apart....important not to forget the person.

Another participant suggested that they felt that their care was more holistic as a result of their visits:

*I think my care is much more holistic following the visits...when you’re working in the clinical area, you’re more focusing on symptom related, you know, you’re just doing because it’s part of the routine of your job description (P8, Phase 2)*

Compassion was also mentioned by participant 11:

*You start to think about it as not just the disease, you think about the person in general and I feel that I have more compassion as a result in my approach to care. [...] I’ve developed my listening skills and how to build trust and developing relationships with people. (P11, Phase 3)*

Participant 11 shared an example of the impact on their practice:

*Pay attention more to the carer. [...] the importance of knowing the carer and building up a conversation to learn more about the person is important and finding out how they are managing. I approach carers more in practice as a result, ask them how they are managing.*

In phase 3, participant 8 discussed the impact of her experiences of the visits on her practice:

*I really understand what it means to listen and to be more sensitive to the needs of the person...importance of just listening.*

All of the participant’s discussed an increased recognition of the value of listening; taking time to listen seemed to shift their perspectives away from a task orientated approach to care. It appeared that listening to the person with dementia and their carers stimulated a holistic and personal understanding of the lived experience of dementia.

*Important to listen, to be there....visits gave a different perspective, far more personal. (P2, phase 1)*

Listening to the person with dementia clearly led to new insights about the experiences of dementia, encouraging participants to appreciate the individuality of the dementia experience. Visits provided an opportunity to learn in a manner congruent with person centred values to listen and try to understand the experience of living with dementia and gain a personal perspective of the lived experiences of dementia. This was gained through listening to the personal experience of dementia which seemed to make participants perceptions of dementia more personal and individualised rather than seeing dementia as a homogenous group.
Avoiding stereotypes [...] sort of labelling someone and that's how they gonna be treated [...] actually going into somebody’s home and listening to how its affected them [...] don’t tar people with the same brush, you know, everyone is very different. Not assuming that everyone with dementia is the same. (P2, phase 2)

This links to Buber’s (2002) theory of relationships that defines relationships in terms of the nature of interactions whereby relations are described in terms of monologue and dialogue. Buber considers dialogue to be the essence of a relationship, asserting that genuine dialogue in relationships is based on mutuality and presence of each of the partners. In contrast, although monologue involves communication there is no relating between the two partners as there is no expectancy of a relationship. Visits provided participants with an opportunity to develop relationships with people with dementia and their carers based on mutuality and presence which they recognised was important in developing relationships.

**4.9.2 Making a Difference**

It could be argued that building relationships is one of the most important skills that student’s learn, participants shared examples of how their experiences enabled them to specifically adapt to the needs of the person with dementia, playing to their individual strengths, and being proactive in their approaches to make a difference. Participants recognised that they could make a difference with simple interventions during their visits supporting the person with dementia and their carer. Participants observed the importance of familiar objects such as photographs within the home to help support the person to maintain a sense of self and identity.

Participant 12 spoke about how they used a different approach to help to engage with the person with dementia, they found out that she loved the music of Elvis from her son during their visit. He stated that he researched Elvis and used this as a conversation point to help engage, connect and develop a rapport. Prior to using this approach he shared how he had really struggled to engage her in their conversations during the visits:

…useful that, to have common interests with your allocated family. The lady was very much an Elvis fan and so was one of my relatives; that was a starting point to kind of like build a rapport…. that was our go-to topic to find out more about that person, and in the second visit we used this as starting point for the…memory book…i will try this in practice more to help me to connect more. (P12, Phase 2)

Stokes (2011) refers to these type of encounters as meaningful moments, whilst Sheard (2008) uses the term butterfly moments; although different terminology is used to describe these moments, both agree that they are moments that are evocative to the person with dementia and can be seen as moments of connection with a person with dementia and the nurse.
Many participants expressed how they had or intended to incorporate what they had learnt into their own approaches to dementia practice. Visits were impactful as participants were able to apply their learning directly to the situation of a person with dementia and their carer in both practice and during their visits, demonstrated by the many examples shared during each phase. Participant 8 shared a story of how she felt that she had made a real difference during her visits; reinforcing the reciprocal nature of the relationship that had developed and reinforcing the importance of working in partnership. As a result of concerns expressed by the carer about the residential home his wife was attending, she suggested and assisted in putting together a ‘This is Me’ book to help staff. They included information such as what the person likes to drink and eat, what she enjoys doing along with a summary of her life history. On a subsequent visit, her husband shared how much of a difference he felt that the book had made to support her care and how he did not worry as much when she went for respite, he felt could relax:

_He said it’s (book) is helping her...when she goes to respite home and she can just point at the picture if she can’t remember...made me feel happy as he seemed much happier about her going to care, it felt like we had made a difference,[...] made me appreciate the impact of the way we care can have._ (P8, Phase 2)

Another participant shared an example of how she supported a daughter who was the primary carer for her mother who had dementia whilst in her practice placement:

_I looked after a lady last weekend who was supposed to be down to have an operation done ...her daughter was told she was going in early and by 3:30 pm she was still there so I rang the daughter and said that everything was fine but she hasn’t gone down yet ... she was really grateful you know she said that is great because all morning I have been thinking she is going to worry. Visits has made me think about things like that more._ (P10, Phase 2)

Many of the participants discussed the impact the visits had on their practice, examples of how they had changed their practice as a result of their experiences have been discussed throughout each of the categories.

Participant 10 (phase 3), discussed how she wanted to continue to make a difference in her practice:

_We may not have as much time to spend talking and listening when we are trained (qualified) it is important to remember that it does not need to take long...5 mins looking at This is Me can make a huge difference to the person and their carer and how they are cared for. [...]_. Helping us to help them I suppose – to make a difference.
4.9.3 Attachment and Reciprocity

Mutuality and reciprocity were evident throughout each phase of interviews and journal entries. The reciprocal nature of the visits and valuing intergenerational relationships emerged frequently in both participant journals and interviews. All of the participants recognised that they, the person with dementia and carer, each contributed and benefitted from their visits. There were numerous references made by participants to; mutual respect (P1, Phase 1), mutual relationship (P5, Phase 2), and mutual connection…we are friends (P1, Phase 3). Participant 1 in phase 1 talked about mutual respect…You feel you are the same, whilst in phase 2 participant 2, talked about being on the same level. Bergum (2003:126) suggests that when nurses engage in therapeutic relationships, the power imbalance often found in professional relationships changes and the relationship becomes more equal. This can be seen in the findings of this study in the reciprocity of relationships that developed.

Feelings of mutuality and reciprocity were evident throughout the study as people with dementia and their carers were seen as valued teachers by all of the participants:

*It felt like it was more of a trading kind of experience. [...] we are learning so much from them about dementia that can help us know more about how to make a difference.* (P9, Phase 1)

*They are not patients, they are participants with us and we’re learning from them as much as they are from us…helping us to develop as nurses as well as understanding dementia.* (P12, Phase 2)

These findings are supported by Rush (2008), who also identified that service users previously seen as the helped were viewed by students as the helpers through their participation in student education. This led me to explore the role of service users as helpful others in the literature. Helpful others, is used by both Eraut (2007) and Morley (2015) to describe patients’ contribution to student nurse learning. The role of service users as helpful others seems to be congruent with person centred care which values the experience of the individual.

Participant 9 reflected about the ease of their engagement with the person they were visiting and how they had helped their learning:

*Within 10 mins, felt comfortable. I felt like I can ask anything…I felt comfortable being there. [...] they were really helping me to understand and learn what having dementia is like and how it impacts on them and their family.* (P9, Phase 1)

Participant 12 expressed that they felt that the person with dementia and their carer benefitted from the contact, enhancing the feelings of mutuality within the relationship:
Some of the things that they have said, they’ve never actually verbally told each other, and it was such a privilege for us to actually come in and facilitate the opportunity for them to discuss it in a health way, and their appreciation for each other, like a couple thanking each other but never had the chance. (P12, Phase 2)

Their experiences enabled participants to discover more about the everyday experiences of a person with dementia and their carer, their aspirations, concerns and the relationships that are important to them. Participants recognised the growing mutuality in their relationships, as longitudinal visits promoted intergenerational relationships/friendships which enabled them to observe changes over time.

Visits...help us to build relationships...see the patient as holistic and think more about how to do nursing care in that way when in placements...think about their lives and their relationships more. (P8, Phase 2)

Participant 1 reflected in her journal, the value of sharing more than a snapshot of the impact of illness on a person:

Life changing...to see the noticeable changes between visits....the benefit of the longitudinal nature (of visits); we usually just get to see a snapshot of people’s lives.

This was echoed by another participant in the focus group:

We only see a snapshot in practice, visits have given us a unique insight into the impact of dementia over time [...] it has been a fantastic opportunity - I have learnt so much about dementia. (FG16, Phase 2)

It was clear that participants learnt to form reciprocal relationships with people with dementia and their carers. According to Morgan and Yoder (2012), person centred care is grounded in therapeutic interpersonal relationships that foster opportunities for individualised and holistic care. Participants spoke of developing communication skills which enabled them to gain insight into how communication contributed to developing relationships, enabling many to connect more with people with dementia and their carers in practice:

Listening and talking with them has made me feel more confident in communicating with people with dementia and their carers, when I am back in practice I try to find time to listen more...take time to develop trust, try to develop more of a relationship with both the person and their carer. (P2, Phase 2)

I felt a lot more comfortable and confident in practice with talking to people with dementia...changing my approach to support them... I feel much more confident talking about dementia and being with people with dementia in practice. (P8, Phase 2)
4.9.4 Authentic Connections

Many of the participants appeared to form authentic connections during their visits, as the person with dementia and their carer shared personal moments of their lives and their experiences of living with dementia. These findings are similar to Haight (2001) and Sorrell (2000:38), who also found that listening to patients’ stories helped students to connect, creating a shared world between nursing students and patients. Visits appeared to promote an appreciation of the relationships they developed over the course of their visits, expressed by participant 1 as:

Felt privileged to be part of their lives…to just listen and really connect with each other. (P1, Phase 3)

Participant 9 (phase 1), also discussed their relationship in terms of:

Really connecting… more of a trading kind of experience.

Feelings of mutuality were also echoed by participant 1 (phase 1):

Mutual respect….You feel you are the same.

The process of mutuality and reciprocity were evident throughout all three phase of the study, demonstrated by the frequent references made by participants to the connections made:

It felt very much like a relationship, it was like a two way kind of relationship in the sense that we were learning about each other… I feel a real connection with them. (P6, Phase 3)

…to share their journey… Really connect. (P1, Phase 3)

We are learning from each other, it is a reciprocal kind of learning. (FG14, Phase 2)

Participants seemed to gain significant personal meaning from their experiences, some related personally with the person with dementia and their carers, relating to their own families making their experiences personal:

They share their life, positive to build a relationship because we are not just ticking the box…we are part of it…their journey. […] Feel that we connected on so many levels – personally. (P8, Phase 2)

Later in phase 3, participant 8 discussed emotionally about the impact this had on them:

You feel more about their problems…I feel more than a friend because he’s at the age of my grandfather, you feel more about your relationship in that way. (P8, Phase 3)
Relating personally was also expressed by another participant during the focus group in phase 2:

*I see it as that could be my nan and granddad and that could be someone related to me...They share their lives and we share some aspects of our lives...what we are doing in our training. It really makes me want to make a difference in practice.* (FG14 Phase 2)

There is a large body of literature that addresses caring and holistic care; underpinned by the nursing theorist Jean Watson (1979), who asserts that it requires *establishing a connection and knowing the patient as a person.* Prolonged contact through longitudinal visits led many participants to expressing feelings of being *present in* relationships, leading them to bring and share aspects of themselves in the relationship which enhanced feelings of *connections,* mutual partnerships as well as friendship.

### 4.9.5 Friendship

There was a sense throughout the data collection of the reciprocal nature of relationships, connections and growing friendships articulated by all of the participants. Many participants discussed their relationships in terms of *friendship:*

*When I first went it was definitely more of a professional persona...until you get to know them and then you can be a bit more of yourself...I would say we became friends...we get on with them really well, and we do care for them. As you let your barriers down, you build that rapport and therapeutic relationship...we are friends...* (P1, Phase 2)

*Part of me felt more like a friend...* (P5, Phase 1)

*...felt very personal it didn’t feel like a professional relationship...like a friendship.* (P6, Phase 1)

*It is a kind of friendship...we really look forward to seeing each other and catching up.* (P11, Phase 2)

Participant 4 described their relationship as *befriending,* which can be seen as different from friendliness, according to Mottram (2009) befriending is about being aware of the other and is purposeful and requires effort.

*I think our second visit we treated it more as being befrienders and we took a cake round and had tea because they are so lovely and we sat and had tea and cake for about an hour and then the wife wanted to chat a little bit and I think they really enjoyed that.* (P4, Phase 1)

These findings contrast with other studies identifying a perceived lack of reciprocity from healthcare professionals and a failure to give something back, in the context of relationships
with older people and people with dementia (Durham and Cannon 2008; Vernooij-Dassen, Leatherman and Olde Rikkert 2011). All of the participants discussed how much they enjoyed their visits and listening to the experiences of people with dementia and their carers. Participant 8 wrote in her journal that it was amazing spending time with them both; whilst participant 1 wrote how she felt privileged to be part of their lives. Participant 4 wrote in their journal about feeling overriding emotion and happiness to describe her feelings about her visits.

It could be argued that by defining their relationships as friendships, demonstrated that participants were able to see how their own perspectives on life had been impacted upon by their interactions with people with dementia and their carers.

4.9.6 Genuine Dialogue

Many of the participants discussed the value of really listening throughout all three phases of the interviews, recognising their role in listening and feeling comfortable with silence, to help develop relationships in practice. The frequent references to active listening demonstrated that it was something they really valued and were aware that they should acquire. Having the opportunity to listen to the person with dementia and their carer was perceived to lead to participants being able to relate to and understand their journey (P1, Phase 3):

> Value of just listening...important to me in the clinical environment to get to know the person because it’s so much easier to understand them. My confidence has progressed as a result of my interactions (visits).... Taking time to listen...recognise the importance of silence; allow time for the person to respond....listening helps to develop trusting relationships...enhance care experiences. (P7, Phase 2)

> Listening, 100%, dementia is very much an individual thing, so I think it is so important to listen...all their experiences affect the way they are now. Time for Dementia has taught me that listening is just so important...moving away from doing to being with.... (P2, Phase 2)

Concerns about time was mentioned in this study by a few participants, concerning practice, as a result of their experiences of their visits, they all acknowledged the value of taking the time in practice listening and communicating with people with dementia and their carers.

> Sometimes it can be difficult to take the time to listen in practice...I think what Time for Dementia has taught me is that listening is so important...it helps you to care for the person...We just listen...the listening part is like careful listening...I have definitely developed listening skills...I do this much more in practice as a result. [...] now try different approaches to care, not afraid to try. (P8, Phase 2)
Baillie et al. (2012a:34) study also reported that participants described how the need to spend time with patients with dementia in practice was *inconsistent with an organisational culture that values speed.*

Participant 2 reflected that: *although it can be difficult to find time in practice:*

> **Listening, 100%, dementia is very much an individual thing, so I think it is so important to take the listen […] all their experiences affect the way they are now. Time for Dementia has taught me that listening is just so important […] feel much more confident in practice. (P2, Phase 2)**

### 4.9.7 Ending Relationships

In phase 2 interviews many of the participants expressed feelings of sadness about ending their relationships, many stated that they would like to keep in touch when the programme ended:

> **Really sad… because they’ve kind of been, you know a part of our lives……Would like to keep in touch, even if just Christmas card kind of thing to find out how they are doing** (P1, Phase 2)

> **Feel sad (end of visits), I would not end the relationship…give a phone call or visit (keep in touch). (P8, Phase 2)**

> **Sad…will keep in touch over emails in between visits – hope will continue…impact it has had to our lives…personally learnt so much. (P2, Phase 2)**

> **It hurts that you are visiting these people and you come close to them…maybe I will visit them in the future. (P11, Phase 2)**

In phase 2, participant 7 discussed that although she felt that she had developed a *real connection* with the person with dementia and their carer, to continue the relationship would be unprofessional:

> **Sort of bittersweet like you’re very happy that you’ve made the connection but you do have to leave it ‘cos it’s, you know, unprofessional to call up every patient…very sad actually, like the end of an era. (P7, Phase 2)**

This was echoed by another participant:

> **You know the boundaries, it’s important to always keep them in mind….the profession we’re going into, you have to have boundaries. (P2, Phase 3)**

Participant 6 discussed their final visit in terms of *closure:*

> **It was definitely the final visit, I don’t think we’ll keep in touch, at the end of the visit we wished each other well, I felt it was quite final. (P6, Phase 3)**
4.9.8 **Summary: Building Relationships**

Findings suggest that visits were a powerful catalyst for participants developing authentic connections that lay the foundation for person centred care. As Beckett et al. (2011:30) proposes:

*Nurses make a difference as much by the ways they relate interpersonally to patients as they do by the technical interventions they use.*

This was recognised by all of the participants in their journal entries and interviews, illustrated by participant 1 in phase 2:

*Biggest impact for me has been the realisation...sometime people do not want answers, they just want people who will listen... realisation of how important human interaction is.*

Visits appeared to create reciprocity which resulted in enriching connections for participants, the person with dementia and their carer, which as Sabat (2001) advocates, positions the person with dementia as a person of worth. The connections that participants made with people with dementia and their carers were real and thus acknowledge the authenticity of the experiences of the visits for them. These findings were similar to those of Casey et al. (2011:1825) study, who also reported that sustained relationships led to close relationships with older people. Many of the participants in this study described the person with dementia and their carer as *friends* and frequently referred to feeling *authentic connections*. Similarly Bollard et al. (2012), also reported that engagement with service users in students’ learning process evoked *authentic connections* and *deeper learning*.

The reciprocal nature of visits emerged frequently throughout all three phases of this study, similar to the *I-Thou* relationship as described by Buber (1970), participants demonstrated elements of trust and mutuality in their reflections on their visits in interviews and journal entries. The focus in practice for many participants resulted in action, moving from *doing care* to *being present*; recognising the importance of engaging and *active listening*. Participants reflected on the importance of *being with* rather than *doing to*, as advocated by Aranda and Jones (2010:254). Visits seemed to have had a profound impact on many participants practice; illustrated by their change of focus from *working on tasks* to *working with*, from *managing patients* to *actively listening to in order to hear the person*. Buber (1970) refers to this process as, the *I-It* relationship becoming *I-Thou* relationship.
Kitwood (1997:119) argues that being present is fundamental to successful interactions, letting go of the drive to do to focusing on being with the person. Benner (1984:57), states that:

> It is the act of “being with” the patient that can make the biggest difference, as in presencing.

This may be viewed as the Art of Nursing. Findings of this study are supported by Spouse (2001), who asserts that a person perspective can be adopted by nursing students through social interactions with patients, arguing that this moves them away from seeing patients as stereotypes and performing technical skills towards being present with them as people. Similar to the findings of Robichaud et al. (2012) study, participants built close relationships with patients by following them on their journey, prompting increased awareness of needs as well as students’ advocacy skills.

Benner (1984) developed the concept of presencing in nursing, suggesting that nurses are often led to believe that they are most effective when doing for a patient, however, her study demonstrated the importance of just being with a patient. Caldwell, Doyle, Morris and McQuaide (2005:854-868) study broadened Benner’s definition about presencing, describing it as knowing the uniqueness of the individual patient; listening actively; caring with confidence, creativity, respect and involving them. Many authors suggest that nursing presence encompasses more than a physical existence, it is a physical, mental, emotional and spiritual presence (Chase, Doona and Haggerty 1997; Caldwell, Doyle, Morris and McQuaide 2005; Campbell and Davis 2011). Visits gave participants an opportunity to listen to the lived experiences of living with dementia, enabling them to immerse themselves in the person’s experience. According to Chase, Doona and Haggerty (1997:7-12) this is the antecedent to presence, suggesting that although nursing students cannot be taught presence they can experience it through behaviours associated with presence such as active listening, empathetic connectedness, and the therapeutic use of self. Ferrell and Coyle (2008) also reinforced the importance of active listening skills with patients, suggesting that:

> Through listening to their patients, nurses can […] help restore wholeness through human connection.

The importance of active listening is, argues Wood (1999:68), as important as talking, suggesting that it goes beyond just hearing as the practitioner is present and sharing the illness experience.

Although presence cannot be taught, findings from this study demonstrate that educational experiences such as Time for Dementia visits may provide opportunities for students to
experience it. Findings suggest that participants’ experienced and established presence though these behaviours, demonstrated in how they spoke frequently about the value of active listening, increased empathy, connectedness and the therapeutic use of self. Rogers (1957) identified three core conditions for a therapeutic relationship: acceptance (unconditional and positive regard), empathy, and genuineness, which Thorne (1991) argues can be seen as the provision of love within the therapeutic relationship. The longitudinal visits in this study appeared to create genuine dialogue as advocated by Buber (Kitwood 1997), between the person with dementia, carer and participants. Affirming terms such as, feeling privileged to be part of their lives (P1, phase 3), felt like a trading kind of experience (P9, phase 1), were frequently used by participants’ to describe their experiences. It was clear that they valued what was shared, demonstrated by the development of mutual relationships. Working with people with dementia as people rather than objects is shaped by Buber’s concept of genuine dialogue (Kitwood 1997). Both McCormack and McCance (2010) and de Vries (2004) suggest that Buber’s philosophy of dialogue greatly influenced nursing and the importance of interconnectedness in the delivery of person centred care.

Participants spoke frequently of their fondness and attachment for the person with dementia and their carers, the reciprocal nature of their relationship and growing friendships, with frequent expressions about enjoying their visits. In addition to increasing the students’ understanding of living with dementia, they frequently talked about feeling better connected to the person as well as feeling a sense of usefulness. These findings are similar to Borbasi et al. (2006) and Nolan (2006) who both discuss the importance of friendship in building a good relationship and providing individualised care with Borbasi et al. (2006:304) suggesting that promoting this relationship made a real difference to patient well-being.

It was clear that participants learnt to form reciprocal relationships with people with dementia and their carers during their visits over three years. The reciprocal nature of the visits and valuing the intergenerational relationships and connections made, emerged frequently in journals and interviews, throughout the three phases of study. These findings seem to have similarities with Hirst and Raffin’s (2001:27) work which held that stories have the ability to transform older adults into valued teachers. Peternelj-Taylor (2004:132) suggests that this experience of connecting through difference with other creates an empowering and transformative experience, one that promotes inclusion over exclusion. Daloz (2000) refers to the types of interactions participants in this study spoke about, where they formed personal attachments with someone they previously viewed as very different from themselves, as constructive engagement with otherness.
Findings may be reflective of students’ developing moral sensitivity, which is described by Lutzen et al. (2006:189) as:

‘Attention’ to the moral values…and a self-awareness of one’s own role and responsibility in the situation.

This was demonstrated by their growing sense of self-awareness that emerged from participation of this study. This moral sensitivity work was used synonymously with ethical sensitivity and may be used to expand understanding of findings of this study. Weaver, Morse and Mitcham (2008) suggests that ethical sensitivity involves moral perception which allows nurses to recognise the person and situational needs to enable them to understand another’s point of view. Findings of this study clearly demonstrate that as a result of their visits participants recognised the person and their experiences of living with dementia. This reflects Kitwood’s overall purpose of person centred care, which Dewing (2008:10) suggests is a moral concern for others.

Participants recognised and discussed the importance of effectively listening to people with dementia. This finding is consistent with Hyde (2004), who suggests that: *listening is one of the basic elements of the life-giving gift of acknowledgement.* Furthermore Jonas-Simpson et al. (2006) in their study of older people identified that when people are not listened to, they feel like a nothing, which they suggested was the equivalent of *social death.* As a result of their findings, they advocate that listening is the basis for all meaningful relationships in professional practice. Maloney (1995:108) asserts that:

Listening is an act of *caring for the individual who is telling the story by providing a vehicle for looking over his or her life.*

Throughout the three phases of interviews, participants identified the value of active listening, many of them spoke about how it made them feel more confident in their approaches to dementia care and identified that it helped them to form caring connections resulting from the relationships formed. Importantly Hunter (2006) contends that active listening promotes a relationship between the nurse and *story teller,* and Sorrell (2000:38) furthers this view by proposing that, *stories help to create a shared world between nursing students and their patients.* Hence as Maloney (1995:108) suggests, *listening becomes an act of caring for the individual* who is telling their story. Fundamentally, as recognised by Buber (1965), listening was vital to the formation of a mutual relationship. The transition that each of the participants experienced as a result of their visits seemed similar to Buber’s concept of relationship (Buber 1965), whereby the participants entered the world of the person with dementia and their care,
moving to an *I-Thou* relationship enabling them to understand life from the perspective of the person with dementia. The act of listening to the experience(s) of people with dementia seemed to inspire self-reflection from participants, resulting in a more expansive view of dementia. This finding resonates with Gorden (2011), who suggests that this act of listening embraces the other. Cummings and Bennett (2012:13) reiterated the importance of listening in nursing during the launch of the Nursing Compassion in Practice strategy, asserting that:

*Listening is as important as what we say and do and essential for “no decision about me without me”.*

McKeown et al. (2010) life story work with dementia patients suggested that medical professionals were better able to understand their patients’ needs and care for them as individuals by developing their practice around understanding patients’ lives. Furthermore Schwartz and Abbott (2007) advocates that listening to stories can encourage deeper knowledge of the experiences of dementia. Listening to the lived experiences of dementia appeared to challenge participants’ assumptions about dementia. Visits enabled participants to see the world through the perspectives of the person with dementia and their carer, influencing their learning and perspectives of dementia and their role as nurses.

Many of the participants’ responses, when recalling the experiences of their visits, were very emotional in tone, illustrating the power of personal narrative to create links (affective), this gave personal meaning and significance of the experience. Consequently participants learnt how to manage strong feelings whilst developing personal relationships and maintaining a professional approach during their visits. Importantly Spouse (2001) argues that increased confidence and the ability to manage feelings and emotions are crucial for developing therapeutic relationships. However, this must be balanced by being emotionally sensitive to others, which Scott (2000) views as an important aspect of nursing, as emotions are needed for the accurate perception of situations in practice as it makes them more aware of clinical cues. This view is also supported by Martinsen (2013) who also argues that emotions open up the ability to understand others and their life world. Kim and Flaskerud (2007:932) suggests that nurses are often more comfortable maintaining a safe distance rather than risking attempts to connect. Participants in this program of visits demonstrated courage to connect emotionally with the person with dementia and their carer despite expressing concerns in earlier phases of getting emotionally involved.

Many participants discussed how emotionally difficult they found ending their relationships at the end of their three years of visits resulting from the connections made. This was evident in
the way that they spoke about the feelings of the reciprocal nature of the visits; the real and authentic connections formed as the person with dementia and their carer shared personal moments of their lives. Nurse curricula emphasises the importance of the nurse-patient relationship and developing therapeutic relationships. Over 50 years ago Hale and Richardson (1963) identified that nursing students are taught the importance of developing therapeutic relationships, little attention is paid to ending the relationship or acknowledging that there may be sadness at its ending. Suikkala et al (2008) study exploring the nursing student-patient relationship from the students’ perspective, identified that there remains a dearth of evidence exploring the notion of relationship ending, especially for student nurses and patients. The topic of terminating relationships is clearly not well addressed in the current nursing literature and could be an area to explore in future research.

Peplau (1988:16) regarded nursing as a significant, therapeutic, interpersonal process, asserting that nurse-patient relationships need to be therapeutic, promoting health and growth. To achieve this, Reynolds (2009) proposes that the patient needs to feel accepted as a person of worth, suggesting that therapeutic relationships should involve communication that helps nurses understand the needs of patients. Visits seemed to provide an opportunity for participants to step back and immerse themselves more fully in learning about dementia. As Browning and Waite (2010:154) contend if the listener can give full attention to the speaker, the listener will have a brand new experience. Findings demonstrate that participants’ experiences led to new ways of seeing dementia as their focus changed to seeing the person rather than just their dementia. These new insights led to assumptions of dementia being challenged, promoting adaptive thinking as they focused less on the drive to do (tasks) and more on being with the person. This enabled participants to recognise the importance of being able to build relationships with the person with dementia and their carers. Finding suggest that visits created opportunities for participants to experience the transformative power of relationships as they gained confidence in their ability to be with people in ways that were authentic and meaningful, inspiring them to move beyond the technical of doing of nursing and open up to the feeling and being of nursing. It could be argued that by defining their relationships as friendships that participants were able to see how their own perspectives on life had been impacted upon by their interactions with people with dementia and their carers. The resulting impact on participants’ learning appeared to be transformative (Figure 12).
4.10 Sub Category 3: Transformative Learning

Figure 12: Components Related to Transformative Learning

Findings suggest that participants had undergone a process of transformative learning as a result of their visits. As previously discussed although the findings are presented as discreet categories they are interrelated. Findings suggest that participants engaged in self-examination, discussing new insights gained, demonstrating changes in their assumptions about people with dementia as well as describing specific action(s) taken as a result of their experiences. These criteria resonate with the work of Brookfield (1987) and Mezirow (2000) on transformative learning.

Some of the participants recognised their experiences as transformational:

*Experiences have been transformational. [...] Dementia does not define the person. Person is more than their dementia. (P5, Phase 3)*

*In practice, we just see them as a patient and focus on their symptoms...visits made me focus on the person [...] has been transformational. (P12, Phase 2)*

Visits with people with dementia and their carers appeared to help move academic learning into a real-life domain for many of the participants in the study:

*Lectures have their place...can only learn so much in a lecture theatre, I mean it’s good for when you're learning about the digestive system and all that, but, when you're learning about experiences, people’s experiences it was invaluable to go to someone’s own home, to hear about that and to actually see that from their perspective, it was really valuable ...it’s really added to my nursing degree. (P6, Phase 3)*

This was echoed by other participants:

*...hearing from the person, it helps you to remember. In lectures we talk about dementia but they can’t explain how it feels to live with dementia, the reality of how it impacts on them and their family. (P1, Phase 2)*
Without getting that personal story from them you don’t know how much the illness has changed him…you need to know something about them personally, helps you to connect, you cannot get that from lectures or books. (FG13, Phase 2)

Increased confidence in dementia emerged as a recurrent theme throughout the interviews and journals. This concept does not seem to have appeared in previous literature about service user involvement in adult nursing, however, this may be due to the fact that involvement of people with dementia in education is under-researched. As previously discussed visiting people with dementia and their carers over 3 years of their dementia journey promoted real connections which in many cases galvanised participants to speaking out for patients. Participants described specific actions taken as a result of their visits as self-examination led to reported changes in behaviour and practice.

I felt a lot more comfortable and confident in practice with talking to people with dementia…changing my approach to support them… I feel much more confident talking about dementia and being with people with dementia in practice. (P8, Phase 2)

I was like comparing myself between the visits and then in practice…I am much more confident in practice now… I am not afraid to try different approaches…knowing that we can make a difference. (P5, Phase 3)

It makes me feel like I can help - even if it’s just a tiny bit […] I now know about support available, like the memory café and other support groups that may be helpful, the couple I visit talk about how much of a difference it has made to them. It’s a good feeling to think I can help. I feel much more confident in practice to recommend different groups knowing they make a difference. (FG17, Phase 2)

Empathetic and emotional learning were both identified as contributory factors to transformative learning.

4.10.1 Empathetic Learning

Participants were able to learn about the subjective experience of dementia from a person living with it. Findings suggest that this enabled them to learn about the human dimension of dementia; prompting some to discuss how it enabled them, as previously discussed to put, myself in their shoes, in what can be seen as empathetic memory arising from their interactions. Visits appeared to be transformational for participants in capturing the essence of person centred care as opposed to professional care:

…you are getting somebody’s personal experience it is very different because you can read about it and you know it is very sad but when you are actually seeing how it impacts on people’s lives …I think it is sort of more I don’t know, you take it on board a bit more I think, you relate it to you own family…not to give it (dementia) a label… (P2, Phase 2)
Similarly Participant 1 (Focus Group, phase 2), spoke about the impact of her visit experiences on her learning and practice:

*Without getting that personal story from them, you don't know how much the illness has changed him...you need to know something about them personally...helps you to connect, you cannot get that from lectures or books. Makes it much more real.*  

(FG13)

Listening to personal experiences of dementia were significant to participant’s development as change agents in practice. Participant 7 shared during phase 1 of her visits an example of how she had advocated for a person with dementia during a clinical practice placement on a ward. Although this experience was not captured during the recording of the interview to enable a verbatim quote to be included as the tape recording ran out, I captured it in a memo written directly after the interview from notes made during the interview (Appendix 19). Although Participant 7 stated that she did not really understand the point of the visits, later in the same interview she shared an example of how her experiences had influenced her to advocate on behalf of a patient with dementia during her clinical placement. Utilising the information contained in ‘This is Me’, she identified that the patient was frightened by shouting and loud noise. She observed that the patient was very distressed on the ward and advocated for her to be moved to another quieter area on the ward away from the nurses’ station. The participant stated that they observed that the patient seemed much less distressed.

Findings suggest that listening to the individual stories of people with dementia and their carers as well as observing the impact dementia had on their lives stimulated learning affectively, experientially and cognitively. Participant’s experiences in essence appeared transformative.

*There should be less Taboo about dementia. Programmes such as Time for Dementia are transformative, gives the opportunity to slowly face our misconceptions about it and gives the new generation of healthcare professionals a better understanding of how to go about approaching dementia as a whole.* (P12, phase 3)

### 4.10.2 Emotional Learning

*I will not forget your story or how it make me feel.* (Schwartz and Abbott 2007:181)

This resonates with participant 4, who felt that the impact of the visits would:

*Definitely, definitely that will be something that I will 100 percent always stick with me you know.* (P4, Phase 1)

Participants appeared to learn from people with dementia and their carers through their emotional connections of hearing about their lived experiences. Responses of participants recalling their stories of listening to people with dementia was emotional, illustrating the
power of the narrative to create meaning and significance. This was similar to the findings of Kumagai (2008) study of medical students who similarly forged emotional links through visiting people with diabetes. Listening to the lived experiences from the person with dementia and the impact on them and their carers elicited emotional reactions in many of the participants:

Prior to visits…just heard the word dementia, but you will see dementia, you will observe dementia and you will feel…it’s more than a word…it’s like we’re going through a journey, and, we are walking with them, they are going through a journey and we are walking with them…it’s a good feeling… (P8, Phase 2)

These insights reflect what Moon (2010:165) describes as emotional insights; resulting in substantial changes in an individual’s perspectives on the world which can be brought about when the person is both emotionally moved and able to understand these emotions through accompanying context.

Participants made many references to the emotional impact of their visits:

I have reflected on it quite a bit in my journal and how hard it is seeing the person you love change. (P4, Phase 1)

I found it quite an emotional kind of journey, almost like going with them…I will miss seeing them. (P1, Phase 3)

Participants shared the emotional impact and perceptions of the impact on their learning about dementia resulting from their visits, many compared this to their learning from lectures or reading about dementia which they identified was detached. During phase 1, I noted in one of my memos my observations that participants’ were mainly descriptive when talking about what they had learned about living with dementia. As their visits progressed (phases 2 and 3) they seemed to: step back, reflecting on ways of knowing dementia and their perceptions of how their understanding dementia from their visits differed from understanding acquired by more traditional approaches such as lectures and books.

It’s around people’s experiences, I think if I had read on paper, you would think you know it is bad but it could be worse for other people. I think on paper you would think that that is quite bad …I think you would you know think ‘oh’ it is very sad but you wouldn’t I think get that level of empathy, you can’t get that level of empathy as you can from actually talking to somebody and actually seeing those emotions and how it effects somebody and you know seeing the sort of bigger picture you know. (P10, Phase 2)

Lectures have their place, but this, definitely adds to my learning throughout the programme, because you can only really learn so much in a lecture theatre…it’s good for when you’re learning about the digestive system, but when you’re learning about experiences, people’s experiences, it was invaluable to go to someone’s own home, to
hear about that, and to actually see that from their perspective, it was really valuable...really added to my nursing degree...much better appreciation of impact of dementia. (P6, Phase 3)

*Time for Dementia* visits appeared to encourage participants to contextualise the theoretical aspects of dementia, enabling them to relate the taught theoretical aspects of dementia to the person’s felt experiences of living with dementia. This supports Smith-Stoner (2011) assertion that educational approaches that involve listening to personal illness narratives, can appeal to the senses; aesthetic, ethical and feelings such as hope, fear and sadness, arguing that it can help students to integrate evidence-based knowledge with the illness experience itself:

…hearing it from her and seeing her looking into my eyes and with her being so honest. I don’t think you get that in a classroom – massive part of learning...emotional rollercoaster. (P5, Phase 2)

you can read up about it and you know what the text books say about it...I haven’t been affected really personally...definitely given me a better insight into it...I definitely wouldn’t have as good of an understanding it hadn’t been for the programme...it enabled me to get to understand dementia. (P1, Phase 3)

Participant 1 reflected how visits seemed to help them to link theory to practice:

…it’s reinforced the learning we’ve had in lectures... it’s been a good way of putting into practice what we are learning in university...really helped my understanding of dementia.

Similarly participant 11 stated that:

Visits have helped link theory and practice, I have been able to apply my understanding and practice skills […] much more confident. (P11, phase 2)

Motivation to want to learn more about dementia and realisation that they could make a difference was echoed by many of the participants throughout each phase of the study. Wanting to learn more about dementia demonstrated participant’s appreciation of their own responsibility to broader their knowledge base to ensure that they are able to effectively work and support people with dementia:

Before (visits) the word dementia was just a word for me, but after going to the visits I wanted to find out more...to go and search…I learnt a lot personally seeing the symptoms and going back and researching…. (Participant 8, Phase 2)

Before the word dementia was just a word to me but after going to the visits I wanted to find out what actually dementia is…I wanted to learn more about it....to make a difference. (P11, Phase 2)

Many of the participants discussed wanting to make a difference, recognising the contribution they could make in their care provision:
Experiences of visits and realising that we can make a difference has inspired to read more about dementia to help me develop my knowledge and skills further. (P12, Phase 3)

...realisation that I can make a difference made me want to engage more and learn about dementia. (Participant 5, Phase 1)

Participants discussed how they developed their communication skills to support people with dementia, and play to individuals’ strengths to provide innovative levels of support. Proficient communication is viewed by many as a key component of person centred care (Brooker 2004; Edvardsson and Innes 2010); whilst Girard (2006) suggests that experiencing what something feels like can lead to action. Participants shared many examples throughout all three phases of how, as a result of their experiences they had or intended to incorporate, what they had learnt into their own approach to dementia.

My communication has developed, there’s nothing nicer than reading through ‘This is Me’ and making someone feel better and reassuring them…makes you feel good at the end of the day to make a difference…To be mindful of how they’re feeling, even if they can’t communicate, ..trying to spend a bit more time to get to know the person. For example, my second family, getting to know what he used to do, if I can bring that into my work, even if it’s five minutes of trying to find out what they did, that might help to build a relationship... make a difference. (P4, Phase 2)

I’ve developed my listening skills and how to build trust and confidence in developing relationships with people. (P11, Phase 2)

I wrote in my memo during phase 3:

Listening to the students talking about their visits has been a huge privilege. It seems to have made them see dementia at a deeper personal level which appears to makes it more memorable for them, promoting new perspectives of dementia and care which has been transformational....

Participant 12 (phase 3) summed up their experiences of their visits:

We read a lot about caring and dementia but it’s when you meet the person that you begin to learn about living with dementia and how we can change our practice.

4.10.3 Summary: Transformative Learning

Knowledge is experience – everything else is just information. (Albert Einstein)

Mezirow (1990 quoted in Mountford 2005:225), suggests that:

Educators who administer programs for the public have a professional obligation to foster transformative learning by offering challenging programs designed to encourage learners to critically examine internalized social norms.
Findings from the study resonate with the work of Moon (2004), who suggests that stories are a vehicle to facilitate learning and reflection rather than merely to impart knowledge. Many of the participants demonstrated an awareness of the thoughts and feelings evoked by their visits, demonstrating the integration of both their head and heart in their learning. This was apparent in some of the conflicts participants shared, reflecting on their existing understanding of dementia and the new perspectives of dementia gained as a result of their visits. This active learning approach of visiting people with dementia and their carers in their own homes appeared to engage participants, resulting in meaningful changes in both personal and professional selves. Findings support Turnbull and Weeley’s (2013:456) assertion that:

*Service user involvement has the power to inspire students to take pride in addressing the little things that means so much to patients.*

The emotional impact of their visits appeared to inspire and motivate participants to develop their practice, reflected by the many examples shared of how they had or intended to incorporate, what they had learnt into their own approach to dementia. Cowdell (2010) argues that educational methods that engage students on an emotional level are more likely to successfully foster healthcare professionals to be empathetic and person centred. This view is supported by Rogers (1983) who suggests that emotion is a pre-requisite for learning and behaviour change. Merriam and Caffarella (1999) and Reeve (2001) suggest that emotion creates purpose in the context of the learning experience. Hearing from service users and carers about their experiences clearly resonated with participants on a personal level and the emotional resonance of listening to lived experiences of people with dementia and their carer seemed to create lasting memories for all of the participants which, according to Brookfield (1987); Dirkx (2006) and Mezirow (2000) is compatible with transformational learning.

Visits initially caused anxiety and uncertainty in some of the participants, especially during the first few visits. Barnett (2007) contends that anxiety and unpredictability are inherent in learning, which Piaget (1985) calls *cognitive disequilibrium*; where individuals are forced to *step aside* and critically reflect on their personal thoughts, feelings and attitudes. Findings appear to indicate some degree of perspective transformations had occurred in participants, which seemed to trigger an intrinsic motivation to act which was reflected in numerous examples shared in changes to their practice. There were numerous examples of transformation of their understanding, perception’s and intended behaviour in future practice encounters towards people living with dementia and their carers. What seemed most striking about the findings was the participants’ development from being anxious about their first
meeting to discussing how they went on to form relationships, indicating that they constructed their service user partners as people.

Studies consistently highlight a lack of confidence reported by qualified nursing staff and nursing students communicating and supporting people with dementia in practice, some staff questioned their own competency and whether they were communicating and providing the most appropriate care for people with dementia (Borbasi et al. 2006; Cowdell 2010; Baillie et al. 2012a; Royal College of Psychiatrists 2013; Baillie et al. 2015). In contrast, visits to people with dementia and their carers seemed to be transformational in capturing the essence of person centred care as opposed to professional care, resulting in the participants seeing beyond the clinical aspects of their role to being able to encompass the human dimension of what nurses do. Encounters with people with dementia appeared to help students to integrate academic learning into real life context, therefore improving quality of dementia learning.

Frank (2012) advocates that listening to service users can enhance understanding to assist health care professionals in building stronger relationships with patients. Baldwin (2005:13) calls service users experience brokers in learning, whilst Eraut (2007) identifies their contribution to student learning as helpful others. A notable omission from Eraut’s study was a lack of detail as to whether this contribution was significant to students’ professional development. In contrast participants in this study shared numerous examples of changes that they had incorporated in their practice as a result of listening to service users with dementia. They frequently expressed how much they valued being exposed to a different, expert type of knowledge that positively supplemented their learning from lectures and reading about dementia. This sense of value argues Glasby and Beresford (2006) is vital, as people with lived experiences need to be valued as they are the experts in their condition. Regular contact and listening to lived experiences made dementia much more real (P5), resulting in humanistic learning as the person with dementia was viewed as more than a set of symptoms. Participants discussed how they had formed emotional connections as they increased their personal insights into the perspectives of person with dementia, demonstrating a more empathetic understanding of their needs which reflects other studies of service user involvement predominantly in mental health education (Morgan and Jones 2009; Towle et al. 2010; Perry et al. 2013; Happell et al. 2014).

The term story catcher was used by Baldwin (2005), to describe what happens when a person listens to a story which stays with them and changes them. This echoes participant’s experiences of their visits as they became story catchers as a result of listening to people with
dementia and their carers which changed their practice, as well as their perspectives of dementia. As participant 4 commented that her experiences *definitely will be something that will 100 percent always stick with me* … Visits appeared to be transformational for the participants in capturing the essence of person centred care as opposed to professional care. These findings are similar to those of Rhodes (2013) and Christiansen (2011) as visits enabled participants' to see beyond the clinical aspects of their role to encompass the human dimension of what nurses do. Moon (1999) contends that if students are making meaningful connections through listening to stories there may be a shift from superficial to more differentiated learning, reflected in the findings of this study. Furthermore Allan (2010) argues that the increasing uncoupling of nurse education and practice puts the importance of learning emotional care at risk, arguing that the move to a competency led curriculum reduces opportunities for students to learn how to manage their emotions. In line with previous research hearing the experiences of service users and carers created powerful emotions with the participants. Hearing a person's lived experiences seemed to resonate with the students on a personal level which seemed to create an experience of state matching as suggested in the empathy literature (de Waal 2008). This seemed to lead participants' to enhance empathetic understandings of the experiences of services users and carers (Tew et al. 2013). This finding is similar to Christiansen and Jensen’s (2008) study on service user involvement which also found that learning from stories can be powerful, findings suggest that it can give rise to learning that is both transferable and reflective. Moon (1999) suggests that if students demonstrate that they are making *meaningful connections*, there is a shift from superficial to more differentiated learning. Findings from all three phases of this study demonstrate that the impact of visits to people with dementia and their carers were transformational for participants, as their perceptions of dementia were changed through their interactions with people who were living with dementia.

4.11 Summary: Findings and Overall Discussion

This Chapter was dedicated to the findings that emerged from the constant comparative method in the data collected over all 3 phases of study. Discussion of findings was integrated with the existing literature which helped to deepen comprehension and increase their strength. The findings that emerged from analysis of the data and the theoretical conceptualisation of adult nursing students' perceptions of their visits with people with dementia and their carers addressed how the aim and objectives of the study were met.

What emerged from the data was the theory of *Whole Sight*, which is a representation of adult nursing student’s *New Ways of Seeing* dementia and their role as adult nurses supporting
people with dementia and their carers. New Ways of Seeing dementia, led to personal and professional growth which led to Adaptive Thinking as assumptions of dementia were challenged. Findings of the study suggested that visits with people with dementia and their carer’s enhanced adult nursing students’ understanding and perceptions of the experiences of dementia which led to new insights and attitudinal changes. As a result of their new insights into dementia, participants’ recognised the importance of focusing less on their drive to do (tasks), consequently their focus changed to being present and building relationships. Transformative Learning was demonstrated by the participants’ self-examination of their practice, which resulted in action, seen by changes to practice taken as a result of experiences of visits. As Bate’s (2004) proposes:

Stories hold the key to humanizing health services. In a field of practice criticised for the many ways it can dehumanize and detach, storytelling in healthcare helps to personalise and connect. (Bate, 2004:68)

The objectives of this PhD study were to explore the perceptions of adult field nursing students’ of listening to people with dementia and their carers and explore if and how this contact impacts on their thinking and practice. This study offers new insights into the impact of service user involvement in adult nurse education, exploring adult nursing students’ experiences of visiting older people with dementia and their carers over 3 years, impacted on their professional learning and practice.

Despite extensive literature related to the involvement of service users in education programmes, mainly in mental health and social work, the scoping review of literature (Chapter 2), identified that there remains limited evidence of its value as a strategy to promote adult nursing students’ learning of dementia. Despite the NMC (2010); the regulatory body for nurses, stipulating service user and carer involvement in their common standards for pre-registration nurse education, the literature review identified that there appears to be little evidence of involvement of people with dementia and their carers in the curricula for adult nursing students. Cooper and Spencer-Dawe (2006:616) also support the introduction of service users’ perspectives in healthcare professionals’ education, arguing that it places service users at the centre of the process, enabling students to make the connection between theory and real life experiences. User involvement of people with dementia in education is underpinned by the principle that the best people to help prepare future nurses are those who have first-hand experiences of dementia. However, it has to be acknowledged that findings of this study combined with experiences from clinical practice were likely to be synergistic.
A significant benefit of the longitudinal nature of the visits for the participants were that they seemed to help them to recognise the complexity of the experience of dementia over time, on both the person and their carer. Findings suggest that benefits of the visits went beyond their enjoyment of spending time with the person with dementia and their carer, as interactions created new insights into living with dementia. Involving people with dementia in pre-registration nurse education appeared to encourage a sense of partnership working and humanism for participants. One of the key contributions of this work was a new understanding of the learning which occurs through the dementia journey, based on the changing perspectives gained during that journey. What emerged from the study of the impact of listening to and observing people with dementia and their carers is represented by the core theory of Whole Sight. This is an innovative finding that opens new directions for future research into improving dementia education, offering new perspectives that should be taken into consideration in developing dementia education in health care curricula.

Limited references were found in the existing literature to Whole Sight. Significantly Hughes, Louw and Sabat (2006:4), suggest that to fully understand human beings in the world, we need better ways of achieving whole sight to enable us to see the person and not just the disease process. They assert that people with dementia should be treated as wholes, with attention given to their lives and relationships. Ferrell and Coyle (2008:110) also propose that:

Through listening to their patients, nurses can [...] help restore wholeness through this human connection.

Findings from this study support this view, as Time for Dementia visits created an opportunity for adult nursing students to see the person, to give attention to the lives and relationships of people with dementia, enabling them to see them as wholes. The theory of Whole Sight is supported by the many references made throughout each phase of the study by the nursing students regarding seeing the whole, whole person, whole sight and new ways of seeing. Findings suggest that initial perceptions and expectations of living with dementia were challenged and support development of educational initiatives such as this, which have the potential to change nursing students' thinking and practice in dementia. These findings are important, as the literature suggests that a negative narrative of dementia creates myths and stereotypes, which contribute to the negative attitudes that many student nurses articulate towards older people with dementia (Beck 1996; Robinson and Cubit 2005; Ryan and McCauley 2005; Beattie et al. 2014; Baillie et al. 2015).
If Health Education Institutes are to help challenge stereotypes of dementia, it is essential that adult nursing students are prepared for the realities of practice, to ensure they can work effectively to support people with dementia in a range of environments and communities of practice. *Time for Dementia* visits served as a foundation to support the constructivist-developmental worldview as advocated by Mezirow (1991), to make meaning of the lived experiences of dementia through interaction and communication. People with dementia are often seen as recipients of care and not as active participants in the nursing curriculum. To try and address this, there is a need to actively involve them in nurse education and the students’ learning process about dementia to avoid tokenistic involvement. Although there has been a shift towards service user involvement in healthcare education, as identified in the literature review there has been limited involvement of people with dementia in adult nurse education. As Koren (2010) contends, a change of attitudes in the profession starts with changes in nurse education. This view is supported by Fry et al. (2015:394), who suggest that universities have a significant role to play in enhancing health and social care services, by educating the future workforce and being a springboard for innovation and enterprise. As Treacy (1987) in Ferguson and Jinks (1994:689) advocates, teacher centred methods of teaching such as lectures as *teaching that fails to touch the students’ reality*. Many of the participants identified that lectures and books did not capture the psychological and social dimensions unique to each person living with dementia. Garno (2010) and Baillie (2012b), both argue that nurse educational approaches that focus on interconnectedness and caring relationships may increase learning professionalism and the capacity to provide holistic patient-centred care. This study offers new perspectives that should be taken into consideration when developing dementia education. Findings suggest that visits focused on interconnectedness and caring relationships promoted a *Whole Sight* focus on the person rather than on their dementia.

Visits appeared to engage participants’ senses in terms of listening, observing and feeling, which Infinito (2003) suggests is key to sensitizing students and encouraging learning which is transformative. As perceptions of dementia were challenged, participants became increasingly sensitized to the health care experiences of people with dementia. This finding resonates with the work of Dirkx (1997), who suggests that when students open their minds to feelings, that this can lead to learning that is transformative, which he describes as *soulful learning*. Findings from interviews demonstrate that hearing the lived experiences of people living with dementia emotionally impacted on participants, the resulting reflections acted as a catalyst for transformative learning. This is consistent with previous research, which supports that listening to people with dementia and their carers, hearing their lived experiences created powerful
emotions in adult nursing students (Rush 2008; Schreur, Fides and Goodbody 2015). Results of this study demonstrate that working in partnership with people with dementia and their carers can clearly enrich nursing students’ education, providing context to theory which is important as the voice of people with dementia can be easily ignored or discounted, especially in education. Lack of engagement with people with dementia in nurse education was illustrated in the scoping literature review in Chapter 2, which highlighted the lack of research studies involving people with dementia in adult nurse education. In the absence of cure, maintaining/improving quality of life is arguably the focus of dementia care. Findings demonstrate that people with dementia can significantly contribute to the learning and development of adult student nurses. Participants’ recognised that providing learning opportunities for non-professional interactions with people living with dementia and their carers outside of the professional care setting provided invaluable learning. Findings suggest that as an educational approach, visits promoted patient centeredness, with participants’ seeing the patient-as-person. As Boykin and Schoenhofer (2001:30) suggest, the challenge of nursing:

*Is not to discover what is missing...but to come to know the other as caring person and to nurture that person in creative ways.*

Findings suggest that, *Time for Dementia* visits are a creative way for adult nursing students to come to know more about the lived experiences of dementia from someone living with it and also their carer. These findings contradict Webber and Robinson (2012), who reported that they found little empirical evidence that service user and carer involvement improved the educational outcomes for social work students. They concluded from their literature review mapping 29 studies, that the prime beneficiaries of involvement were the service user and carers themselves, arguing that the evidence suggested that they were empowered by their involvement in supporting students’ education (Webber and Robison 2013).

In contrast, findings from this study suggest that a process was apparent for participants, whereby interactions during their visits helped to create new insights into dementia, consequently this illuminated their understanding of dementia and the impact on the person as well as their carer. As previously discussed, the majority of people with dementia continue to live in their communities in their own homes. The value of initiatives such as the *Time for Dementia* visits, is that they extend clinical placement experiences beyond the traditional ones currently utilised by many HEIs. Sharing experiences with a person with dementia and their carer helped to create a shared world between them and could be seen to reflect a shift in power and role in the relationship between student as learner and patient as educator. It is clear that visits with people with dementia and their carer helped to create a shared world of
mutual connection between them and the participants. Service user involvement in adult nurse education underpins the principle that the best people to help prepare future nurses in dementia care are those who have first-hand experiences of dementia.

The emotional impact of hearing the lived experiences of people with dementia and their carers emerged frequently throughout all three phases of interviews, reflective journals and focus group in phase 2. These findings support Cowdell’s (2010) assertion that educational methods that engage staff on an emotional level are more likely to prompt nursing staff to become more person centred and empathetic. Personhood is viewed by many as one way to help address stigma, as Milne (2010:229) proposes:

Promotes a lens that sees the person behind the dementia.

Findings suggest that the Time for Dementia visits helped to promote a lens for adult nursing students to see the person behind dementia; to enable them to explore their life experiences, past and present lives, which have shaped their experiences. Participants’ recognised that personalised information booklets for people with dementia such as This is Me, provided key information on relationships and care preferences, enabling them to connect and engage with the person more in practice. Participants were able to explore the lived experience(s) of people living with dementia rather than focusing on their diagnosis, which resonates with Pacquiao’s (2008:190) work in giving the nurse:

The ability to see the world from the point of view of the other.

As previously explored, the philosophical position of relationship throughout this study was informed by the thinking and work of Buber (2002). The impact on participants reflect Buber’s concept of genuine dialogue, whereby visits reinforced the position of working with people with dementia as people rather than as objects. Findings from this study are supported by those of Kumagai (2008) study on the impact of a Family Centred Experience (FCE) programme, which involved medical students listening to patient’s illness narratives. Similarly Kumagai (2008:656) evaluation also identified that as a result of their experiences, students’ experienced what he called intentional dialogue, which he reported required them to engage their whole selves, their experiences, personal values, beliefs and perspectives. Kumagai (2008) suggested that the FCE programme encouraged perspective-taking and broadened medical students’ perspectives of living with chronic illness, strengthening the findings of this study that involving service users in healthcare education results in more humanistic, person centred approaches to care.
Findings from this study suggest that visits and the resulting dialogues engaged participants in different ways of thinking and knowing through multiple domains of cognition, affect, and experience. This provided deeper insights, promoting greater understanding and empathy and offering the possibility of learning and change, going beyond clinical, technical skills and empirical knowledge to include moral, aesthetic and personal ways of knowing (Carper 1978). The process; of knowing the patient appears to be an integration of the four patterns of knowing in nursing practice identified by Carper (1978): empirical, ethical, personal and aesthetic which is at the core of holistic nursing. Aesthetic knowing is used by Carper (1978) to describe the process of how nurses’ show empathetic understanding of how a patient may feel. Participants demonstrated aesthetic ways of knowing in many ways through their discussions of experiences and impact on their practice. Personal knowing was evident through the frequent examples of participants’ insightful observations of the impact of dementia on the person and their carer, demonstrating engagement with the person and humanistic concern:

It’s not just seeing dementia as a case, you see the person behind it. (P11, Phase 3)

Ethical knowing was evident when participants’ discussed changes to their practice and examples of how they had advocated for the person with dementia, demonstrating an understanding of what was wrong, and their moral obligation of what ought to be done in specific situations. Unlike previous study findings on the perceived impact of service user involvement (Christiansen 2011; Gidman 2013), participants from this study provided examples of how exposure to poor practice had actually translated into changes to their practice as they were moved towards action. Participants shared many examples throughout the study, which demonstrated the nuances of caring compassionately for people with dementia as well as ethical knowing:

I’ve seen other people in practice and I don’t always agree with how they treat people with dementia...they get cross, but shouting at people and getting cross doesn’t do anything does it? There’s been a couple of times I have stepped in – I am like, I’ll deal with this person. I feel confident…not to hold back (P2, Phase 3).

I feel more confident to step in and say, ‘why don’t we try’… instead of holding back. (P8, Phase 3)

This discussion shows that participants felt confident to stand up for patients in their care, rather than acquiesce; demonstrating practice that upholds the ethical principles of justice. Evidence from previous studies suggest that nursing students often lack the moral courage to intervene in practice (Bradbury-Jones et al. 2007; O’Mara et al. 2014; Rees et al. 2014; Bickhoff et al. 2016).
Personal knowing was evident throughout the study, demonstrated in the *authentic connections* that participants’ experienced and examples shared of their personal journey and what the visits meant to them.

> See visits as helping to aid me develop as a caring nurse…definitely feel that I am more empathetic towards people with dementia and their carer […] experiences have made me think about what sort of nurse I want to be when I qualify. (P7, Phase 3)

The evidence of how their experiences impacted on their learning was evident in the many examples shared by participants, of how their learning was translated into behaviour and practice changes as a result of reflecting on their values, beliefs and assumptions of dementia. The *Time for Dementia* visits offer an alternative approach to the traditional block placements often utilised in nurse education and evidence suggests that they have the potential to promote new insights into dementia. Visits depart from traditional practice-based learning and factual learning through lectures, findings suggest that this approach incorporates alternate ways of knowing, which led to *New Ways of Seeing dementia* and resulted in *Whole Sight*. Arguably the act of informally reflecting on their experiences, as each participant shared their experiences in interviews and reflective journals, also impacted on their knowing of dementia nursing and personal knowing. Some of the participant’s suggested that their involvement in the research process enabled them to realise how much the visits had impacted on them:

> Personally learnt so much, it’s not until I think back over the last 3 years of visits that I appreciate how much I have learnt about dementia and gained from the programme. (P2, Phase 3)

Educators are continuously looking for new ways to engage nursing students in order to enrich the nursing curriculum and the learning process. This is important to ensure that nurse education remains current, and reflects caring for an ageing population and the increasing numbers of people living with dementia. In order to do this, there is a need to evaluate current nursing curricula, as well as explore and evaluate different educational strategies. Findings suggest that educational initiatives that provide opportunities for non-professional interactions, such as *Time for Dementia*, can encourage students’ self-awareness through reflection on practice and self, and fosters a humanistic, person centred approach to learning about dementia in nursing.

The educationalist Freire (2000:87) asserts that, *education is the practice of freedom*, suggesting that the role of educators is to encourage nursing students to learn through encounter rather than merely dispensing knowledge. Smith-Stoner (2011) also suggest that by using education initiatives that try to appeal to the senses (aesthetic, ethical and moral) and
feelings (sadness and hope), it may encourage students’ to integrate knowledge and meaning of the illness experience for the person. Since the Willis report on education (Willis, 2015), there appears to have been a change in the focus in education, to try and find a better way forward for preparing adult nursing students for future practice. The *Time for Dementia* visits provided a genuine opportunity to learn through listening and understanding the lived experiences of dementia, directly from a person with dementia and their carer, in a manner that is consistent with person centred values as advocated by both Brooker and Latham (2016) and Kitwood (1997). Findings from this study suggest that educational initiatives, such as *Time for Dementia*, that promote informal direct interactions with people with dementia and their carers in their own homes, encouraged nursing students to see the *person behind the dementia patient* in their practice. As Norman (1996:315) advocates, instead of abstractly learning about dementia, health care professionals should be encouraged to see the individual as a *person, and not an illness*.

Many of the participants recognised and discussed the value of *active listening*; throughout all three phases of the interviews; recognising their role in listening and feeling comfortable with silence to help develop relationships in practice. Ferrell and Coyle (2008) reinforced the importance of active listening skills with patients, suggesting that:

*Through listening to their patients, nurses can […] help restore wholeness through human connection.*

The importance of active listening is, argues Wood (1999:68), as important as talking, suggesting that it goes beyond just hearing as the practitioner is *present and sharing the illness experience*. Although presence cannot be taught, findings from this study suggest that educational experiences such as *Time for Dementia* visits may provide opportunities for participants to experience it. Findings suggest that participants’ experienced and established *presence* though these behaviours, demonstrated by how frequently they spoke about the *value of active listening, increased empathy, connectedness* and the *therapeutic use of self*. Findings suggest that listening to a person’s experiences of illness provides complementary perspectives to biomedical knowledge, helping participants’ to gain a more holistic approach that includes factors related to the person and their social context. Listening to a person’s experiences resulted in participants’ perceptions of life with dementia becoming more individualised and personal. Participants’ assumptions about dementia appeared to have been challenged as interactions and observations of the impact of dementia stimulated learning in the affective, which is associated with emotions and values acquisition, as well as the cognitive (knowledge of dementia) dimensions of learning (Bloom 1956). The development of
professional values, according to Shultz (2009), is linked with the affective domains of learning. According to Kritzer et al. (1996), the affective domain includes emotions, feelings, attitudes and moral reasoning as well as self-adjustment and self-image. Findings suggest that visits engaged the affective domains of participants’ learning, illustrated by the new theory of Whole Sight, which encompasses New Ways of Seeing dementia, resulting in changes to practice.

Visits also promoted self-exploration as many of the participants’ explored their own values, resulting in an increased self-awareness of themselves and what being a nurse meant to them.

There is no quick fix… there is no cure; nursing care is about supporting the person to try and improve the quality of their life and living. (P8, Phase 2)

This importance of dialogue and the resulting impact on the affective and cognitive domains of learning is supported by Kumagai and Naidu (2015:283) who propose that:

Dialogues allow for the inclusion of affective and experiential dimensions in addition to intellectual/cognitive domains in learning, for an emphasis on discovering new perspectives, insights, and questions instead of limiting participants solely to an instrumental search for solutions.

Numerous references were made by participants of wanting to find out more about dementia in the literature to help them link theory and practice demonstrating that visits impacted on students’ cognitive leaning:

Before the word dementia was just a word for me, but after going to the visits I wanted to find out what more- to go and search […] I learnt a lot personally seeing the symptoms and going back and researching […] helping me to link theory to practice. (P8, Phase 1)

The research study findings are supported by the work of Fazio, Seman and Stansell (1999:6), who suggest that engaging emotionally can be seen:

When people begin to hear (and see) things differently, they can think about things differently, and ultimately act differently.

As Rush and Barker (2006:259) advocate, service users added an inspirational factor to education through sharing their life experiences. It could be argued that when students only encounter people with dementia in a clinical setting such as acute care they are more likely to think of them as patients rather than people. Consequently, students in clinical setting placements, as Simons et al. (2007) suggest, are more likely to focus on the immediate clinical issues presented by the service user, whereas interacting with service users in different environments enables them to see beyond the clinical issues and into the wider context of their
lives. Visits opened up the homes of people with dementia as an aspect of the real world, which Schneebeli et al. (2010:33) advocates:

Normalises the experience of illness, enhancing the development of the idea of patients as people.

The new theory of Whole Sight reflects how visits enabled participants to perceive people with dementia, as Smith (1997) suggests, as being a person such as I, encouraging students’ moral imagination as advocated by Murdock (1956), by entering the world of the person with dementia.

Reflecting on how visits have impacted on me…there was a lady I was struggling with, I had to remember, she’s someone’s wife, mum…you have to remember they’re human, you have to adapt to their world as they cannot adapt to ours. (P2, Phase 3)

The core category of New Ways of Seeing, illustrates the impact of entering the world of a person with dementia, as visits challenged participants’ perceptions and attitudes towards dementia. Participants reflected on their pre-conceived attitudes:

See dementia in a different light […] realise that we often disable people with dementia in practice, assumption is they cannot perform own care tasks. Visits have helped me to reframe dementia […] focus on the person more and what is important to them. (P12, Phase 3)

The Time for Dementia programme provided adult nursing students with a genuine opportunity to learn in a manner congruent with person centred values, as it provided participants with an opportunity to understand the experience of living with dementia from someone living with it. Preparing nursing students’ for clinical practice is a key component in the adult nursing curricula; findings suggest that visits promoted an opportunity for adult nursing students to develop a deeper understanding of dementia and its impact on the person and carer. Findings from the interviews, focus group and research journals suggest that visits to people with dementia and carers enhanced understanding of the experiences of dementia. This was demonstrated by the students’ ability to begin to recognise the complexities of dementia to enable them to see the person with dementia from a holistic perspective, reflecting a biopsychosocial framework of dementia. Time for Dementia visits are an example of an innovative educational initiative that can be implemented by HEIs to ensure that, as Willis (2012) proposes:

Person centred care should be: a golden thread that runs through all pre-registration education (Willis 2012:2).
The next Chapter presents a summary of the findings of participants’ first career destination and 6 month follow up findings of the last phase (phase 4) of the study. Discussion is integrated with existing literature which is also seen as data in grounded theory.
Chapter 5: Findings and Discussion: Impact on Career destination

5.1 Introduction

This Chapter addresses objective 4 of the study: To look at nursing students' perceptions of the impact of the visits on their future career choices.

The development of experiential methods of dementia education to prepare healthcare students and ensure they have a realistic understanding that their roles involve caring for older people living with dementia is advocated by the WHO (Prince 2016). As discussed in Chapter 2 (section 2.18), although numerous studies have explored intentions to work in aged, and less so, in dementia care settings; no longitudinal studies were found exploring adult nursing students career destination in relation to working with older people with dementia. Although findings of this study add to understanding that it is possible that interventions such as Time for Dementia may have made it more likely to consider working in the community in the future, further research would be needed to look at this. Participants’ career preferences (phases 1-3), and career destination (phase 4) is summarised in Appendix 10.

5.2 Discussion of Findings

During phase 4 follow up, three of the participants (P1, P2 and P12), shared their perceptions of the continuing impact that they felt the visits had on their practice, as registered nurses, six months after qualifying and commencing their first posts.

I believe the visits have helped me empathise more with patients and their relatives. It’s given me a better understanding...as a result I know there are many places that I can signpost relatives to. I feel much more confident in supporting people with dementia and their carers. (P1)

I would say that our visits have definitely impacted on my practice as I often think about how my confused patients must be feeling and how disturbing being in a strange place must be for them, especially during night shifts. I remember this was a big issue for our family when the gentleman was hospitalised and his wife had to stay with him in order to keep him calm and safe. I hope that with the majority of my patients, I am able to reassure them and help to keep them calm. (P2)

I feel that Time for Dementia prepared me with the knowledge and practical methods in interacting with such service users with dementia. For example, using re-orientation boards, ensuring that during night time hours the unit has minimal noise etc. All in all, it was a privilege having had the opportunity to be in the programme. (P12)

Although limited, there is evidence of continuing impact on participants' suggests that participating in an innovative educational initiative like Time for Dementia, may serve as a
foundation for future nurses’ understanding and preparation to care for people with dementia. Although this information was not part of phase 4 data collection, consent was gained from participants to include. I reflected that I would like the opportunity to re-interview the participants post doctorate, to explore their perceptions of the impact of visits post-registration. This would enable me to explore the longitudinal impact of the visits on participants’ practice after qualifying as registered nurses on their practice and career destination.

Two key categories were identified that appeared to impact on career destination, although they are discussed separately they are interrelated:

- Working environment
- Influence of placement

5.3 **Context of Working Environment**

Although all of the participants acknowledged that whatever speciality they chose to work would involve caring for older people with dementia, only two participants (P5, P9), identified that they wanted to work specifically with older people and people with dementia as a career option:

*I see myself working with people that have dementia or with people that have neurological - that was also something that I am interested in […] I see myself working with people that have dementia in the future when I qualify. (P9, Phase 1)*

Unfortunately participant 9 withdrew from the study after phase 1, consequently there was no follow up data on career destination.

As a result of their experiences of visits, participant 5 considered working with older adults:

*I never really considered working in a sort of elderly ward or with elderly people but now I will definitely consider it. […] visits made me step back and enjoy getting to know the person and their journey. (P5, Phase 1)*

In phase 4, participant 5 discussed that she was still considering working with older people as a career option after a preceptorship rotation. She perceived that she would benefit from a period of preceptorship to help with the transition from moving from student to registered nurse:

*I actually enjoyed my elderly care placement as well so I was thinking maybe in the future, but surgical rotation at the moment. […] feel I need to consolidate my learning first. (P5, Phase 3)*
Findings suggest that working environment experiences contributed to participants' choices in where they saw themselves working. Working in a nursing home was perceived by participant 3, as their worst nightmare choice.

*Want to be an ED nurse, I like the fast pace of work […] A nursing home is probably my worst nightmare of a career destination. (P3, Phase 1)*

When questioned further, she shared that she had volunteered in a nursing home prior to commencing her studies, and this opinion was based on her experiences that working in the nursing home was physical and repetitive. Similar views were expressed by participant 2, she discussed that working with older people was: very heavy and a six-week placement had really taken its toll:

*Loved all placements, do not know yet where I want to work, but not care of elderly …placements seems understaffed, the work is heavy. (P2, Phase 2)*

This finding is consistent with the work of Smith (1992); Happell (2002) and Kloster, Hoie and Skar (2007), who also reported that nursing students' identified the negative attributes of working with older people, such as generating a higher workload and being physically demanding.

Most of the participants made the decision to work in primary care in the community, either as a first career destination \((n=4)\), or after they had consolidated their practice \((n=3)\). Being able to focus on the person in their own environment and feeling that they may be more autonomous in their role, were some of the reasons given that seemed to impact on their decision to work in the community:

*I feel like I can be a bit more myself …you can do a bit more in the community than the hospital because I just felt like when you work in a hospital you're just ticking the box. (P8, Phase 3)*

When asked to discuss what she meant by this, she shared that in practice her experiences were that in hospital:

*Focus of practice is on doing, it is very task orientated. It is more about getting the job done as quickly as possible rather than about the person.*

This was echoed by another participant:

*Loved the fact that you kind of manage your own caseload, I love the fact that you visited patients in their own homes, they are very different in their own homes…there was that whole realisation of how lonely people can be, just kind of making a difference…a nice feeling. Really enjoyed my visits as part of Time for Dementia as you
get to know the person more than in acute care environments where the focus is on the task and (clicks fingers) move on to the next job to do. [...] There is little satisfaction at the end of the day. (P1, Phase 3)

Participant 6 also discussed that the working environment was important to her and influenced her decision to work in the community rather than on a hospital ward:

I like how you can go into a person’s home and focus entirely on them...whereas on a ward you’ve got six, eight, twelve people to look after all at one time, and you’ve got to think about med rounds and, you know, oh, everything, all at the same time. I would much rather be in the community, that kind of environment suits me better. (P6, Phase 3)

Findings suggest that the experiences of their visits appeared to reinforce participants’ decision to work in the community:

Working in the community will give me more time to nurse. To be the kind of nurse I want to be, [...] experiences of visits has made me realise the importance of time to connect and be present in care. [...] to make a difference. (P8, Phase 3)

Wanting to make a difference to patients was discussed by all the participants throughout the study and validated their decision to become a nurse. As participant 1, phase 3 described:

I want to make a difference, even if it just one little thing, you know...to know that I have made a difference in someone’s life today, like that’s...what I want to do as a nurse.

Wanting to make a difference appeared to be seen as connecting with patients:

To go home at the end of the day knowing that you have made a difference, how important human interaction is to the person. (P8, phase 3)

Nursing tasks are important as you have to do dressings and things like that, but it is the way you do it [...] smile and engaging with them...that is what makes a difference to the patient. (P12, phase 3)

Participants’ career decisions appeared to be supported by their ideals of nursing practice and wanting to make a difference in their working environment.

5.4 Context of Placement

Although some of the participants in phases 1 and 2, (P2, P8, P12) expressed that they were keeping an open mind about their first career destination, they all acknowledged that placement experiences were impacting on their future career choices:

Decided at the beginning of my training that I needed to keep an open mind because I knew full well that I would love something and then I would go on to my next placement and love that and you can’t have it all. I definitely would have said it would have been
with older people in some sort of setting… I am kind of still trying to kind keep my mind and my options open. (P1, Phase 1)

In phase 3 many of the participants (n=5) (P2, P5, P8, P11, P12), discussed that they felt they needed to consolidate their practice through a preceptorship rotation programme before working in their chosen area of practice (Appendix 10).

Participant 12 discussed their decision to accept a surgical rotation preceptorship post, he perceived that this would help to increase confidence and consolidate learning in preparation to work in community where he ultimately wanted to work. This finding is consistent with a study by Bloomfield et al. (2015) of primary health care as a career option, which suggested that newly qualified nurses who wanted to take up a post in the community felt that they needed to consolidate their skills in acute care prior to applying for community posts.

In the future I am leaning towards community nursing once I have my foundation nursing skills developed. (P12, Phase 3)

Although only one of the participants (P5), discussed working with older people in the future (section 4.1), she discussed that she had accepted a surgical rotation post because she enjoyed her surgical placements and felt that she needed to gain more confidence in my skills and consolidate practice:

My first placement was surgical and I loved it…I actually enjoyed my elderly care one as well so I was thinking maybe in the future but surgical rotation at the moment. (P5, Phase 3)

Participant 2 also discussed that her decision to work in surgical rotation was based on her surgical experiences throughout her training, suggesting that the continuity of accepting a post where she had her supervised practice placement, was important in helping her transition from student to registered nurse:

I quite like the surgical side of nursing [...] enjoyed my placements. Staff are really supportive and I get to learn so much. (P2, Phase 3)

Wanting to work in an area that was supportive was also discussed by another participant:

I have more experiences in medical areas so that’s why I think [...] you want to go for where you have good practice experiences… good learning opportunities. (P11, Phase 3)

This study’s findings are supported by Wareing et al. (2017), their UK study also reported that practice placements played a key role in career choices of student nurses especially in their
final year of study. Similarly they found that nursing students are more likely to apply for posts in the placement area they found to be more supportive and developmental.

Some of the participants accepted posts which they felt would help them prepare for future career preferences. Participant 4 accepted a job as a Practice Nurse as she felt that it would be good preparation for her, helping to build her confidence and consolidate her practice to prepare for working in A&E. As a Practice Nurse she acknowledged that; I am sure I’m going to come across lots of patients with dementia, she also discussed how she felt that her experiences of Time for Dementia visits helped her to feel much more confident in her practice to support people with dementia and their carers. Her reasons for choosing A&E in the future were:

I want to be busy, I like the fast pace, many people with dementia come through A&E, the experience of my visits will help me to improve their care as I feel much more confident in dementia care.

In contrast, participant 8 discussed working in A&E to help prepare her to work in the community:

I think that working in A&E will help consolidate my skills, help me to prepare skills and confidence to work in the community (P8, Phase 3)

Placement experiences and the working environment were identified as important considerations for participants’ and appeared to impact on their choice.

5.5 Summary: Career Destination

Price (2009) posits that career choice is a dynamic process that requires ongoing adjustment and is not merely a one-time decision. Some of the participants appeared to be undecided in their career choices during the early phases of the study (Appendix 10). Participants 2, 8 and 12 were undecided in phase 1, whilst participants 2 and 5 were undecided in phase 2. This finding is consistent with other studies exploring career destination, which suggest that many nursing students remain undecided where they would like to work in the early stages of their training (McCann, Clark and Lu 2010; Spouse 2000; Happell 1999), and decisions change over time.

Although participants’ placements had an impact on their career choices, as participants’ appeared to apply for posts in placements they enjoyed, the working environment was also identified an important consideration thereby impacting their choices. Participants stated that
they preferred the ‘more relaxed pace of community nursing’ compared to acute care environments. Working in the community appeared to support their ideals of nursing practice and ‘wanting to make a difference’ to patients. Some of the participants in this study made the decision to work in primary care in the community either as a first career destination \((n=4)\) or after they had consolidated their practice \((n=3)\). Although it has to be acknowledged that the findings are limited due to the number of participants, they suggest that the visits may have made the participants more likely to work in the community in the future. Due to the small number of participants’ further research is required to explore this in the future. Findings do appear to contrast with previous research findings where acute area settings involving technology, focusing on curing illness and saving lives, were perceived by adult nursing students as more attractive work options than other settings such as the community (Happell 2002; McCann et al. 2010; Stevens 2011; Norman 2015, Iersel et al. 2016). Hapell (1999); Palese et al. (2007) and Bloomfield et al. (2015) also identified that primary care was a less popular career choice for newly qualified nurses, as opposed to acute technical areas such as critical care which were more popular career choices. Both Koh (2012) and Lui et al. (2013) reported that most of the nursing students in their studies felt that working in the community was not real nursing, reporting that students’ perceived that clinical skills were not really needed in the community as patients will not recover. Stevens and Crouch (1995) argues that this is a result of nursing students being socialized into preferring a cure rather than care approach, which they term the care-cure dichotomy. In contrast, participants in this study talked about wanting to work in an area that they felt they could ‘make a difference’, suggesting that working in the community would enable them to be ‘more person centred’ and ‘less task orientated’. This contributed to the development of the theory of Whole Sight, illustrating participants’ journey of making sense of what being a nurse meant to them as well as their broadening view of dementia, encompassing the whole person which resulted in New Ways of Seeing dementia.

Brown et al (2008) study of adult nursing student placement experiences, identified five foci of attention which they reported were demonstrated by nursing students over time: self, course, professional care, patient and person as focus. They posited that the extent to which nursing students are able to achieve focus is dependent on their exposure to, what they refer to as, enriched environments of care. Evidence from the findings of this study suggests that visits may help to create enriched environments for learning, encouraging adult nursing students to focus on the person rather than the patient. Recognition of the importance of spending time with people was frequently referred to throughout the study by all of the participants. Findings
suggest that this resulted in participants being more person centred in their approach to dementia care, as opposed to a task orientated approach to care. Visits appeared to encourage participants to reflect on their approaches to people with dementia in practice, examples shared demonstrated action as a result of their experiences:

In practice […] we **do things** we don’t take time out to listen to the patient …we focus on the medical side, it’s the quick fix side.[…] following visits, […] spend more time listening and getting to know the person and their carer in practice […] think about what is important to them and not what I need to do. (P8, Phase 1)

Many of the participants in phase 3 (n=5), identified they felt that a period of preceptorship was essential to help to develop their self-confidence and consolidate their skills to work as a registered nurse. These views reflect the DH (2010:11) definition of preceptorship as a:

*Period of transition […] to develop their confidence as an autonomous professional, refine skills, values and behaviours.*

Both the NMC (2006, 2015), and DH (2010d), advocate that newly qualified nurses have up to one year of preceptorship to help them develop their self-confidence and consolidate their training and support their transition from student to registered nurse. Four of the participants in the phase 4 follow up, were working in acute areas as part of a year-long preceptorship rotation programme. These participants perceived that a period of preceptorship was helping them consolidate their training and support their preparation to work in the area where they eventually wanted to work. This finding is supported by other studies by Robinson and Griffiths (2009), Higgins et al. (2010) and Whitehead et al. (2013), which also reported that student nurses wanted a period of preceptorship in order to develop and consolidate their skills in practice after qualifying. Furthermore a systematic review of supporting newly qualified nurses in the UK by Whitehead et al. (2013), suggested that newly qualified staff reported that they benefitted from a period of preceptorship, indicating that it helped to promote self-confidence, enabling them to become an autonomous professional.

Whilst it is not possible to generalise from such a small sample, this study’s findings suggest that the programme of visits to people with dementia and their carers may have made participants more likely to consider working in the community in the future. In order to attract new nurses to work with older people with dementia it is important that there are opportunities for nursing students to undertake practice placements in a variety of areas such as the community. As explored in Chapter 2, an ageing population means that the numbers of people with dementia requiring healthcare will continue to rise, consequently the nursing workforce must be prepared to care for people with dementia. As Baillie et al. (2015) argues education
must adequately prepare adult student nurses during their training to ensure that they have a realistic understanding that their roles as registrants will involve caring for older people living with dementia. All of the participants in this study acknowledged that wherever they chose to work, their role would involve the support and care of people living with dementia. This was demonstrated by participant 1 who summarised in phase 3:

*Whatever the setting, as an adult nurse, you will be working with older people with dementia….you can learn so much from experiences with them. Our experiences of the visits has taught me so much, how important it is to focus on the person. All healthcare students would benefit from the experience that we have been given to help prepare them.*

Although it is important to recognise that although some of the participants had no desire to work specifically with older people with dementia, this does not necessarily mean that they had negative views; rather that other areas of work were more appealing to them.

It may be possible that the programme may have made participants more likely to consider working in the community in the future, however, further research is needed to explore if participating in an innovative educational initiative, like *Time for Dementia* impacts on career choice. Educational and experiential interventions are viewed, by many, as key to try and address the disinclination of some nursing students to work with older people in practice (Heliker et al. 1993; Haight et al. 1994; McKenzie and Brown 2014; Baillie et al. 2015). Caring for older people living with dementia needs to be considered a core nursing role and central to adult nursing practice. Meaningful contact in undergraduate education may change career preferences, however, further research is needed to look at this. To attract new nurses to work with older people with dementia, it may be valuable for there to be opportunities for nursing students to undertake visits with older people with dementia outside of acute settings; this may well also be relevant to other health professions.

This Chapter has presented a summary of the findings of participants’ first career destination, discussion was integrated with existing literature as this is also seen as data in a grounded theory approach to help deepen comprehension. Although findings suggest that the programme may have made participants more likely to consider working in the community further research is needed.

The next Chapter concludes this thesis, how the research question was answered and the original contribution of the findings to the body of knowledge is discussed. A critical analysis of the strengths and limitations of the study is presented. Broader implications of the study with
recommendations for nurse education and practice as well as further research are explored, followed by a reflection on the impact of the doctorate on broadening my knowledge base.
6 Chapter 6: Evaluation, Recommendations and Conclusion

6.1 Introduction

This final Chapter presents a discussion of the strengths and limitations of the study and considers the recommendations for nurse education and nursing practice. The recommendations follow a critique and evaluation of the research and are compared to existing research to strengthen rigor. Suggestions are also given for further research deriving from the findings of this study. To conclude the thesis I consider the impact that doing my PhD had on broadening my own knowledge base.

6.2 Research Evaluation: Strengths and Limitations

This section reviews the chosen methodology in light of the findings that have emerged. An initial scoping literature review identified gaps in the current research of people with dementia and their carers' involvement in the education of adult student nurses. On reflection, limitations have been identified in the scoping review. Only peer review studies were included in the inclusion criteria. It is acknowledged that, including grey literature such as unpublished work (e.g. dissertations and conference proceedings), may have added more contextual information to the review of service user involvement. The review was limited to adult nursing students only, however, there may have been transferrable learning from other student groups, such as mental health and social work students, as service user involvement has been a regulatory requirement for these groups for greater length of time.

Although the strengths and limitations of the study design were articulated and acknowledged in Chapter 3, there were times during the study that I questioned whether there were other approaches that could have been taken and whether this would have led to a different outcome.

An ethnographic approach may have been appropriate to explore and uncover more about the culture of homebased visits as opposed to the hospital setting, especially as the setting of the visits was the person with dementia and their carer’ own home. This approach may have enabled a different exploration of the impact of power relationships. As a member of the nursing faculty, I was interested in listening to the viewpoint of the students of their experiences of being involved in an innovative dementia education initiative. I propose that the strength of the constructivist grounded theory approach is that it supported my aspirations to embrace the voices and meanings of all of the participants, enabling their perspectives to emerge from the
data. Participants were new to the experience of being a student nurse and visiting people with dementia and their carers in their homes, the grounded theory approach allowed them to develop and build on their perceptions of visits, enabling me to capture the essence and richness of their experiences over 3 years. As Mills, Bonner and Francis (2006) suggests, the constructivist grounded theory approach enabled me to be present in the research, by collecting the data and as a voice in the reporting of the research. I feel that my familiarity with dementia and the students, as a lecturer, aided me to gain a more in-depth of understanding of the research findings. The constructivist grounded theory approach adopted for this study, ensured that the adult student nurse participants remained key players in shaping the findings of the study. As Horton and Walsh (2017) asserts, grounded theory achieves relevance by demonstrating that the study deals with concerns of the participants’ rather than those of the researcher.

A further limitation of this study that is acknowledged, is that the experiences of people with dementia and their families were not explored as part of this study. Service user experience is being collected and informs part of the mixed methods evaluation of the wider Time for Dementia study as discussed in Chapter 1.

Although service users helped to inform this study through their involvement with the wider Time for Dementia steering group, which meant that they were involved in the initial discussions about the concept of this study, it is acknowledged that they could have been more involved in the research process. As a result it is acknowledged that there was a lack of patient and public involvement in the research process for this study.

The core category, New Ways of Seeing, became evident through constant comparison from analysis of the data. Glaser and Strauss (1967) suggest that the core category is accountable for what is happening, New Ways of Seeing represented the main patterns of participants’ behaviours throughout the study, which resulted in the new theory of Whole Sight. However, as Glaser (1978) acknowledges, a limitation of grounded theory is that even though concepts are grounded in the data, they are not proven but only suggested: Therefore, it has to be acknowledged that the theory generated from this study remains with the confines of myself and the experiences of the adult nursing student participants of the study. As Glaser and Strauss (1967:40) proposes:

*The published word is not the final one, but only a pause in the never ending process of generating theory.*
Parahoo (2014); Cooney (2011) and Cutliffe (2003) all assert that credibility in methodological rigor of grounded theory can be strengthened by the process of reflexivity, consequently a research journal was kept throughout the research process to justify the decisions made throughout. I found the process of reflexivity an important component of doing a longitudinal study over 3 years to account for my interpretations, whilst reflecting on my success and failures. It also encouraged me to keep a sense of perspective as I have a tendency to be quite critical of my work.

Data generation was restricted to adult nursing students participating in the *Time for Dementia* visits in one Health Education Institute, consequently the small number of participants involved in the study means that the findings cannot be generalised to a wider population. Although this study is local, I argue that local qualitative studies can provide depth of rich data that may inform and inspire future research. It also has to be acknowledged that student selection involved those willing to participate, which may have led to lack of negative experiences being reported as students who enjoyed their visits may have been more willing to participate in the study than those who did not.

A limitation of this study is that although findings suggest that *Time for Dementia* visits may have made participants’ more likely to consider working in the community in the future, due to the small sample size, further research is needed. Further research using an ethnographic approach, may have uncovered more about the culture of home-based visits as opposed to the hospital setting as the constructivist grounded theory approach is, on reflection, not the most appropriate to look at the impact on career destination.

An inductive rather than deductive approach to collection of data and analysis was used throughout, to ensure that the experiences of adult nurses remained central to the development of a new theory for understanding the impact of visiting older adults with dementia and their carers in their own homes. This enhanced the validity of the results of the study. Preliminary codes during phase 2 were validated with a focus group, which further aided interpretation of findings. Emerging categories were repeatedly checked with my supervisors. Although limitations in the study are acknowledged, I suggest that the strength of the study lies in its contribution to the body of dementia knowledge, which resulted in recommendations for nurse education and nursing practice.
6.3 Contribution to The Body of Knowledge

As identified by Bleakley (2014), there is a need to understand the processes of learning with, and from, as well as about patients as foundational to health professionals' education. The scoping review revealed a lack of outcome-focused research on service users with dementia and their carers’ involvement in adult nurse education. The lack of knowledge of how adult nursing students learn from service users with dementia and their carers constituted the gap in the literature. This gap led to the research question:

*What are student nurse perspectives on the impact of longitudinal home visits to people with dementia and their carers?*

The research question was left intentionally broad because according to Glaser (1992) and Strauss and Corbin (1998), a broad research question can reduce the potential restriction of a narrow focus, arguing that if a focus is too narrow it can limit understanding of relevant concepts. This study offers new insights into the impact of service users with dementia and their carers on adult student nurses’ perceptions of dementia. One of the key contributions of this work was the development of the theory of *Whole Sight*, which resulted from participants’ *New Ways of Seeing* dementia. During analysis it became clear that this was an innovative finding that opens new directions for future research into improving dementia education and practice.

Although the study was set in England in one Higher Education Institution, the expansive literature about the attitudes of student nurses towards older people with dementia indicates the global interest in the issue of dementia. Although fewer studies have focused on older people with dementia; the projected increase in dementia worldwide and the major contribution that nurses have in caring for people with dementia, it could be argued that the results of this study could have international implications. As previously discussed education has been slow to respond in ensuring future health professionals have the skills to support people with dementia (Pulsford, Hope and Thompson 2007; St Cair Tullo and Gordon 2013; Alushi, Hammond and Wood 2015). The *Time for Dementia* visits were initially developed as a response to calls for innovation in integrating mandatory dementia education into healthcare professional education. Visits provided nursing students with an experiential learning experience which findings demonstrate informed their practice and increased their understanding and confidence in dementia care.
Career destination findings also offer new insights into the impact of an innovative educational initiative like *Time for Dementia*, on adult nursing students’ career destination. Participants’ career decisions appeared to be supported by their ideals of nursing practice and wanting to make a difference in their working environment. Findings support the assertion that educational and experiential interventions are key to try and address the disinclination of some nursing students to work with older people in practice (Heliker et al. 1993; Haight et al. 1994; McKenzie and Brown 2014; Baillie et al. 2015). Findings add to the current lack of research focusing on career decisions of UK adult nursing student nurses which was identified in Chapter 2 (section 2.18).

This study offers new perspectives that should be taken into consideration in developing mandatory dementia education in the health care curricula. The next section discusses recommendations that can be drawn from this study for nurse education and nursing practice as well as identifying further research deriving from the findings of this study. To try and increase its strength, existing literature is integrated into the discussion of recommendations.

### 6.4 Recommendations: Nurse Education

This research is timely as it followed the introduction of mandatory dementia education in Health Education Institutes for undergraduate healthcare professional students. Literature around improving practice in dementia care emphasises the significance of education focusing on person-centred care and establishing meaningful interaction with people with dementia (Robinson et al. 2010; Eggenberger, Heimerl and Bennett 2013, Surr et al. 2018). A variety of reports and policy documents support the development of educational initiatives that foster a deeper understanding of older adults with dementia for undergraduate nursing students (DH 2009; DH 2012 Willis; 2012; Surr et al. 2018).

Contributing to the body of knowledge of dementia nurse education, findings of this study add to the evidence that involving people with dementia in education is a powerful learning resource for adult nursing students. Although the focus of this study was on adult branch nursing students’ perceptions only, it could be argued that the findings are relevant to healthcare educators in a variety of disciplines of healthcare. Healthcare educators need to recognise the valuable learning opportunities that all healthcare students’ can gain from listening to people with dementia as an educational strategy. Results indicate that the visits created a positive dementia discourse, shifting the focus from seeing dementia as a disability to a more balanced view of dementia, whereby participants could see potential and hope. This finding supports
Vernooij-Dassen and Jeon (2016), who argue for the replacement of the disaster scenario with one of living well with dementia, to try to create a more positive dementia discourse. This adaptation perspective is also reflected in the World Health Organisation definition of health, which focus on the ability of a person to adapt to self-manage when living with chronic conditions.

In order to keep nurse education contemporary, curricula needs to reflect the increasing ageing population and people living with dementia, consequently it needs to evaluate how dementia is integrated into the nurse curricula. The issue of an additive approach resulting in crowded nursing curriculum is frequently explored in nurse education literature (Diekelmann 2004; Ironside 2004). It was important for me, as a nurse educator, to integrate dementia into the nursing curriculum in a meaningful way, which impacted on the nursing students’ understanding and experiences of dementia, rather than merely add to an already crowded curriculum. Findings from this study have implications for education, future healthcare professionals must be supported to enable them to meet the demands of an ageing society and the increasing numbers of people with dementia. Most of the participants (interview n=8) (focus group n=4) in the study, had no experience or minimal experience of dementia prior to their visits (Table 4 pg. 70; Table 5 pg. 75). Visits to people with dementia and their carers are one approach that nurse educators can implement, to proactively help prepare nursing students to care for older people with dementia, to try and improve the quality of dementia care. From the participants’ perspective, findings suggest that visits reduced their fear of dementia and impacted positively on their confidence, consequently this encouraged them to adopt more flexible and creative approaches to connect with people with dementia and their carers. This was illustrated by the many practice examples of new behaviours and skills shared throughout this study which demonstrated participants’ New Ways of Seeing dementia. Benner (1984:13) posited that one of the challenges that many student nurses undergo during their training is to go from a detached observer to being an involved performer. Results suggest that participation in the Time for Dementia visits can serve as a foundation, enabling nursing students to explore the experiences of dementia from the perspectives of people with dementia and their carers. Findings demonstrate that participants moved from being detached observers to become involved performers with people with dementia and their carers.

Findings of this study contribute to the scant literature evaluating the impact of the contribution of people with dementia and their carers to the education of adult nursing students. As explored in Chapter 2, pre-registration programmes are the initial socialisation into professional practice, therefore it is essential that education sets the standards of future practitioners. Findings
illustrate how visits and listening to people with dementia and their carers, can help to engage students emotionally, which resulted in increased empathetic responses and engagement with people with dementia and their carers. Evidence from this study supports the recommendation for more interactive and engaging methods for educating healthcare professionals (Cowdell 2010; Willis 2015; Prince et al. 2016). As explored in Chapters 2 and 5, educational experiences have been shown to influence nursing students’ career decisions. Preparation of adult student nurses is an important concern in relation to the future workforce, an ageing population means that the numbers of people with dementia who require healthcare will continue to rise, and consequently HEIs must help to prepare the nursing workforce to care for people with dementia. Career destination findings, discussed in Chapter 5, suggest that educational initiatives such as *Time for Dementia* that involve listening to a person’s experiences of living with dementia, can serve as a foundation for future adult nurses’ career destination as well as preparing them to care for people with dementia in practice.

As a nurse educator I was interested in finding out about the experiences and perceptions from the viewpoint of the adult nursing students participating in the *Time for Dementia* program. As Mills, Bonner and Francis (2006) suggested, constructive grounded theory aims to investigate participants’ reality from their perspective, therefore the aim of the research supports the approach chosen. If nurse educators are to encourage nursing students to learn about the whole person and not just about the disease process, nurse education needs to evolve in order to reflect this. Levin (2004) argues that it is important to involve service users and carers at early stages in nurse education to ensure that students’ recognise the value of partnership approach from the start of their training. As Fry et al. (2015:394) proposes; HEIs can play a significant role in enriching health and social care services by educating the future healthcare workforce through being a springboard for innovative educational activities. The need for improved dementia education and its potential to improve our current systems is clear, at both an undergraduate level as well as post-graduate level (Department of Health 2009; 2015).

Older people with dementia are commonly seen only as recipients of care and not as active participants in care and education. In order to try and change this, Kleinman (1988) suggests that patients and families narratives of their illness experiences need to be more central to the educational process. Findings from this study suggest that participants, as a result of their interactions, were able to see the person as individuals with lives and experiences beyond their dementia. Participants identified that it was often difficult for them to see past the patient element to the person behind their dementia when in clinical practice, mainly due to the focus of care on tasks and doing. As explored in Chapter 2, many studies have highlighted the need
for nurse education to address the negative discourse of dementia. Findings from this study adds strength to the development of educational initiatives that challenge stereotypes about dementia, encouraging students to see each person with dementia as a unique individual. Engagement of people with dementia promoted students' understanding of the personal and embodied experiences of dementia. Findings suggest that visits can be viewed as promoting an individualised lens for understanding the dementia experience. This research study goes beyond adult nursing students’ perceptions towards dementia; it offers new insights into developing innovative educational initiatives of dementia education that moves beyond the common didactic teaching often used. The findings suggest that the impact of visits such as Time for Dementia, may provide a frame of reference for future practice (Mezirow and Associates 2000:5).

Participants’ personal knowing of the person behind the disease, enabled them to explore their contribution to dementia practice, strengthening the evidence supporting service user involvement in healthcare education. Educational activities such as listening to the personal experiences of people living with long term conditions such as dementia needs to be recognised as valuable as developing clinical competencies in practice. Notably, findings suggest that participants were able to develop an understanding of the importance of being rather than just doing in practice and how they saw themselves as future nurses. Supported by Kitwood (1997:43) who advocates that, care should focus less on what is done and more on how it is done, people with dementia need others to hold their story and respond to them as thou in the uniqueness of their being.

What this study adds is that innovative educational initiatives such as Time for Dementia, can serve as a foundation for future adult nurses broader understanding of dementia. It could also be argued that visits are a way to make nurse education more socially accountable, broadening nursing curricula to involve the expertise of people with dementia and their carers. Although the study was limited to adult nursing students, visits could also be implemented into the education of qualified nurses to improve dementia care. Findings from this study supports the recommendation to include service users with dementia and their carers in the education of healthcare professionals to help to address deficits in the care of older people with dementia.

Visits to older people with dementia and their carers in nurse education support Willis’ (2012) assertion that:

*Person centred care should be a golden thread that runs through all pre-registration education* (Willis 2012:2).
Although these recommendations are discussed in relation to undergraduate adult nurse education, they may also apply to the education of other healthcare professional students.

6.5 Recommendations: Nursing Practice

A variety of national reports and policies have identified the need for an informed and effective dementia workforce, as there is widespread concern around the quality of dementia care by healthcare professionals both internationally and nationally (Alzheimer’s Disease International 2012, DH 2016, Martin, O’Connor and Jackson 2018). Martin, O’Connor and Jackson (2018:13) scoping review of gaps and priorities in dementia care in Europe, highlighted a critical need to empower staff in dementia care, arguing that lack of confidence is often associated with dehumanising care in practice. It is essential therefore, that adult nursing graduates are adequately prepared to work effectively with older adults with dementia in practice. In order to do this there is a need for more innovative approaches to placements that capture students’ interests. Unfortunately Ironside et al. (2010) identified that community settings are used less frequently than acute; a survey of 531 associate degree nursing programmes suggested that acute care is predominantly used for placements. Findings suggest that innovative clinical models, such as Time for Dementia, create enriched environments which enabled the nursing students to develop a more positive view of dementia, as a result of fostering a broader understanding of the needs of older people with dementia.

Findings of this study demonstrated that visits resulted in adult nursing students getting to know the person with dementia, as a person who is not defined by their dementia symptoms. These new insights resulted in New Ways of Seeing dementia, leading to Whole Sight which appeared to encourage participants to look at their own approaches to care provision, which resulted in new ways of working. Many of the participants’ questioned their roles and position within the care process, leading to more empathetic and self-aware practice as they realised that they could impact change and serve as change agents in dementia care. This was demonstrated by the numerous examples shared by participants of the impact on their practice, they questioned and changed their own approaches to people with dementia and their carers. Many of the participants’ demonstrated moral courage thereby acting in a manner consistent with professional values, demonstrating an increased self-awareness of what being a nurse meant to them. Some participants challenged practice which they observed did not support the person with dementia. Participants discussed examples of action as a result of their experiences, sharing examples that demonstrated moral courage to step in and not confirm to outdated practices. This finding contrasts with previous studies that suggest that nursing students often
lack the moral courage to intervene in practice (Bradbury-Jones et al. 2007; O’Mara et al. 2014; Rees et al. 2014; Bickhoff et al. 2016). Unlike previous study findings on the perceived impact of service user involvement (Christiansen 2011; Gidman 2013), participants from this study were able to provide examples of how exposure to service users had actually translated into changes to their practice as they were moved towards action.

Experiences of visits encouraged adult nursing students to become more patient-centred as they began to understand dementia in terms of biopsychosocial understanding as opposed to a biomedical understanding. Boyle (2000) proposes that a biomedical understanding of dementia often positions a person in a state of decline, rather than as a person with remaining potential, which McCormack (2004) suggests, can result in people with dementia being treating as things rather than as a person. As a result of their visits, nursing students talked about hope, rather than seeing the person in a state of decline they spoke about seeing a person with remaining potential. Participants’ focus of care were challenged as they reflected on how care impacted on patients, understanding the importance of therapeutic relationships in care provision rather than just focusing on tasks. These findings contrast with Brown et al. (2008) study, which found that building and sustaining relationships was seen by nursing students as less important, care was achieved at the expense of seeing the patient as a person. Findings from this study support the development of innovative training initiatives and endorse Willis’ (2012) commission recommendation that the experiences of patients should be at the heart of nursing education to help improve dementia nursing practice.

In summary, interventions such as the Time for Dementia visits may encourage adult nursing students to consider working with older people and older people with dementia as visits served as a foundation for future nurses’ understanding and preparation to care for people with dementia. Although the recommendations are discussed in relation to undergraduate nursing practice they could also apply to other healthcare professionals. The next section explores recommendations for future research.

6.6 Recommendations: Future Research

As my doctorate is coming to an end, I have had an opportunity to evaluate my study and reflect on what I would like to do next. I reflected that I would like an opportunity to re-interview the participants of my study to ascertain their perceptions of their experiences of their visits post-registration. Follow up would enable me to continue to explore the longitudinal impact of the visits on the participants after qualifying as registered nurses. Exploration of the use of
journals and students’ attitudes towards completing journals is also an area that would be interesting to explore at a post doctorate level. Although nurses are taught the importance of establishing a nurse-patient relationship, little attention seems to have been paid to the cessation of these relationships. Future research could also address the gap identified in the current literature of how to support students to end nurse-patient relationships.

As discussed in Chapter 5, recommendations for future research also include exploring the longitudinal career destination of adult student nurses at 12, 24 and 36 months post qualification, as there was no change identified in career destination between phase 3 and 6 month follow up (phase 4). While there are limitations in generalisation from a small sample such as this, the finding that most of the participants chose to work in the community as either a first or future career destination, differs from previous studies on the career destination of adult nursing students. The findings suggest that participants realised that they can be active in their contribution to care, make change, and serve as change agents in dementia care.

Meaningful contact in undergraduate education may change career preferences. To attract new nurses to work with older people with dementia, it may be valuable for there to be opportunities for nursing students to undertake visits with older people with dementia outside of acute settings; this may well also be relevant to other health professions. Evidence suggests that working in dementia care services are often under-valued in comparison to other areas of health and social care, attracting nurses to work with older people and older people with dementia is a concern nationally and internationally. Further research is needed to explore how education can support a workforce strategy that can grow and sustain a workforce, which is equipped to provide care that meet the care needs of older people with dementia, irrespective of the setting, now and in the future.

Findings from the study suggest that the contribution that older people with dementia and their carers can contribute to healthcare professional students’ learning and development and is a concept worthy of further exploration. Future research could also explore whether the intervention of visits may be generalised to other long term conditions, evaluating the effectiveness of this strategy to develop an understanding of how knowing someone’s biography can facilitate an empathetic connection between the nurse and older adult. As advocated by The World Alzheimer Report (2016), we need to develop education initiatives that enable the next generation of health care professionals to rise to the challenge of dementia. Further robust research is required, nationally and internationally, to evaluate the efficacy of dementia education for healthcare professionals, to support the consistency of dementia education in Higher Education Institutes.
6.7 Reflexivity: Impact of the Doctorate: PhD Journey

As previously discussed in Chapter 1, the mandate to include dementia in nurse education was the driver for me to explore innovative education initiatives in nursing curricula that may help to prepare nursing students to support people with dementia. I acknowledged that when I commenced my study, I felt intimidated by the language and had little understanding of the theoretical basis of research. However, as Charmaz (2006:105) asserts; My Aha moment of deciding the methodological approach came after lots of reading, reflection and discussions with my supervisors. Although the use of reflexivity is important in demonstrating rigour and credibility especially in grounded theory, I feel that the process helped to really enhance my journey as a novice researcher. I used this writing opportunity as a method of discovery as a new qualitative researcher my own philosophical perspectives are developing. Throughout the process of research, I considered my influence through being reflexive, as Richardson (1992:104) points out, being reflexive ensures that I am always in the corner somewhere. Although many critics propose that reflexivity can result in self-indulgence (Finlay 2002; Cutcliffe 2003; Bishop and Shepard 2011; Holloway and Biley 2011; Doyle 2013); as a doctoral student I found the process of reflexivity facilitated a greater awareness of the nature of the insider/outsider experience of being a researcher. As articulated by Males (2009: 930); as a novice researcher I entered a:

World of productive disequilibrium through self-reflection, collegial dialogue and on-going critique.

Although some researchers use the third person in academic writing, I reflected early on in my writing that this perspective would not allow me to express my feelings and emotions. Consequently, I reflected, writing in first person helped with the co-construction which further supported the constructivist approach chosen. Reflexivity enabled me to explore and gain a greater insight into the relationship between participant(s) and my role as researcher. Throughout the process, I was mindful of the power imbalance of the researcher-participant relationship, ensuring that the voices of participants were heard (Wilson and Neville 2009). One of the criticisms of interview responses, especially of participants known to the interviewer, is that their responses can be a product of a prepared mind (Lowes and Weeks 2006; Ferguson et al. 2006). As I listened to the interview transcripts it became clear that this was not the case, as participants described many specific instances of how their perceptions had changed after listening to the person with dementia and their carer.
As I progressed through my research journey, I reflected that as my confidence improved I felt that my interview style became more relaxed and comfortable, which I felt engaged the participants more. I was conscious throughout the research that although my professional experience, in my opinion, enhanced my sensitivity to the data and analysis, I did not want my insights to prevent me from identifying different perspectives that I may have missed. In the earlier stages of my study my own learning was enhanced through the critical colleagueship of my doctoral supervisors and colleagues. I reflected that as my confidence increased in the use of grounded theory memoing became more effective. The impact of listening to the participants sharing experiences and perceptions of their visits was inspirational at times, I reflected in one of my memos during phase 2:

As I listened to P1, I am inspired by their talk of hope and love and the resulting examples of changes they have made in practice. I am seeing the impact of the visits in a new way, the experience of the visits was clearly inspirational; prompting some to critically consider their attitudes towards dementia... just as they talk of 'new ways of seeing dementia', I too am seeing the impact of their visits in new ways.

My reflective diary catalogued the difficulties that I experienced through my doctorate journey as well as the many light bulb moments I experienced during my journey. Throughout the research process I discovered the work of theorists and academics who informed my knowledge of both research and dementia education. Although I have worked in dementia nursing and adult nurse education for many years the process of doing my doctorate reinforced the importance of research particularly in areas that are familiar. Listening to participants, reading their transcripts and journals gave me a sense of understanding the Whole journey, which also illustrates the experience of my research journey as well as reflecting the findings of the study and theory Whole Sight.

The PhD contributed significantly to my evolving identity from teaching fellow to academic; I was promoted to Lecturer in older adult care during phase 3 of the study. Without doing this doctorate this transition would not have been possible. As I progressed through my PhD, I realised that I needed to disseminate my research findings to a broader audience through conference presentations and posters as well as publications. Presenting at conferences has enabled me to discuss my research work with members of the audience and was a really valuable experience. My work was received with interest and it was exciting to discuss my work with other conference participants who also had an interest in dementia education. Dissemination of my research is summarised in Appendix 23. The process of doing my PhD has fuelled my interest in continuing research in higher education in the area of dementia, older person care and nurse education.
6.8 Conclusion

Dementia is a key 21st Century societal health and care challenge. How well we respond to the projected doubling of the numbers with dementia in the next generation depends on the quality of our future workforce. As previously explored, multiple deficits have been identified in current dementia education by UK policy makers, which resulted in a Department of Health mandate that all undergraduate healthcare curricula should include dementia. Pre-registration programmes socialise healthcare students into professional practice by the interaction between theory and practice. They set the foundations for the future quality of NHS health and social care by building the knowledge, attitudes and competencies required. Educators continuously look for ways to try and engage students, enriching the curriculum and the learning process. There are active and unanswered questions about how to enable healthcare education to engage with the new and growing challenges posed by dementia and other long term conditions. Here I explored one particular novel approach, the Time for Dementia Programme, which had at its core longitudinal learning from people with dementia and their carers as mentors.

What emerged from the data was the theory of Whole Sight, which resulted from participants’ New Ways of Seeing dementia. The findings suggest that as a result of their visits, participants reframed their perceptions of dementia, as attention was given to broadening their view of dementia, to encompass the person’s lives and relationships. They saw and treated people with dementia as wholes, not just focusing on their dementia. Participants recognised the person with dementia as separate to, and more than their presenting illness. Findings suggest that this increasing awareness led to a person-centred shift in participants’ practice, demonstrated by examples of a more humanistic approach to supporting people with dementia in their clinical practice, demonstrating that New Ways of Seeing result in Whole Sight.

These findings add to the evidence that involving people with dementia in education is a valuable learning resource for adult nursing students and contributes to the body of knowledge on dementia nurse education. Although the focus of this study was on adult nursing students only, the findings may be relevant to healthcare education across disciplines. Healthcare educators should recognise the valuable learning that students’ can gain from coming to know and listening to people with dementia as an educational strategy. Results indicate that the visits created a positive dementia discourse that led to changes in practice. This study offers new insights in developing dementia education that focuses on interconnectedness and caring relationships, promoting a Whole Sight focus on the person rather than on their dementia.
While there are limitations in generalisation from a small sample such as this, the finding that most of the participants chose to work in the community as either a first or future career destination, differs from previous studies on the career destination of adult nursing students. Further research is needed to explore if meaningful contact may change career preferences and attract new nurses to work with older people with dementia.

This study offers new insights in developing dementia education that focuses on interconnectedness and caring relationships, promoting a Whole Sight focus on the person rather than on their dementia. Educational policies should reflect these findings to help achieve a workforce that meets the needs of people with dementia and their carers. Community based educational initiatives like the Time for Dementia programme, have the potential to introduce a broader concept of dementia to nursing students, enabling them to recognise the difference they can make to the lives of people with dementia and their carers. This research is timely as it followed the introduction of mandatory dementia education in Health Education Institutes for undergraduate healthcare professional students. Contributing to the body of knowledge of dementia nurse education, it offers a new direction to address how mandated dementia education is incorporated into the adult nurse curricula, findings may well also be relevant to other health professions, nationally and internationally.
7 References


Alzheimer’s Society (2007) Dementia UK: A report into the prevalence and cost of dementia prepared by the Personal Social Service Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at Kings College London for the Alzheimer’s Society. Dementia UK, London.


de Vries, K., Drury-Ruddlesden, J., Gaul, C. (2016) ‘And so I took up residence’: The experience of family members of patients with dementia during admission to an acute hospital unit. *Dementia* 0(0):1-19.


Hovey, R., Craig, R. (2011) Understanding the relational aspects of learning with, from, and about the other. *Nursing Philosophy* 12(4):262-270.


Martinsen, E. (2013) Toward a medical ethics that cares: a theoretical and normative study of ill-being and care in medicine. Oslo: Faculty of Medicine, University of Oslo.


intensive care unit: Increased proportion of family speech is associated with increased satisfaction. *Critical Care Medicine* 32:1484-1488.


Wilson, P; Mathie, E; Keenan, J; McNeill, E; Goodman, C; Howe, A; Poland, F; Staniszewska, S; Kendall, S; Munday, D; Cowe, M; Peckham, S. (2015) ReseArch with Patient and Public InvOlvement: A RealiSt evaluation – the RAPPORT study. Health Services and Delivery Research 3(38).


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### Appendix 1: Search Strategy

<table>
<thead>
<tr>
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<tr>
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<td>S2</td>
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<td>S3</td>
<td>pre-registration nurs*</td>
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<td>undergraduate nurs*</td>
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<td>student nurs*</td>
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<td>patient *</td>
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<td>client*</td>
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<td>service user*</td>
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<td>carer*</td>
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<td>S22</td>
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<tr>
<td>S23</td>
<td>S19 or S20 or S21 or S22</td>
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## Appendix 2: Study Characteristics and Findings

<table>
<thead>
<tr>
<th>Author</th>
<th>Practice Field</th>
<th>Aims</th>
<th>Methods</th>
<th>Findings, Conclusions and Recommendations</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basran; Dal Bello-Haas; Walker; Macleod; D’Eon; McKague; Chopin; Trinder (2012)</td>
<td>first year medicine first year pharmacy first year physio 2nd year nutrition 3rd year nursing 4th year social work</td>
<td>Evaluate the outcomes of a senior mentoring program</td>
<td>Mixed methods Pre and post survey (Polizzi aging semantic differential Interdisciplinary Education Perception Scale) Focus group 1 year follow up online survey</td>
<td>Significant improvement of perceptions of older men and women. Changes appeared to be sustained at one year follow up Minimal change seen in interprofessional attitudes</td>
<td>Single site Researchers involved in the intervention</td>
</tr>
<tr>
<td>Christiansen (2011)</td>
<td>Nursing students (Adult, Mental Health Child Learning Disability)</td>
<td>Evaluate the use of patient digital stories</td>
<td>Qualitative phenomenographic semi structured interview n=20 3rd Year students</td>
<td>4 Themes identified : Learning resource; Emotional experience; Reflective experience; Transformative experience</td>
<td>Single site No mention of the relationship of researchers to participants</td>
</tr>
<tr>
<td>Costello and Horne (2001)</td>
<td>Adult nursing students</td>
<td>Evaluative study</td>
<td>Quantitative n=23 67/69 questionnaires completed Small group discussions with students (Quasi-Statistical content analysis)</td>
<td>85% - greater understanding of patient problems. 6% - learned nothing</td>
<td>Single site Sample is small Researchers’ role is not clear (analysis)</td>
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<tr>
<td>Reference</td>
<td>Students:</td>
<td>Methodology</td>
<td>Findings</td>
<td>Study Type</td>
<td></td>
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<tr>
<td>Gidman (2013)</td>
<td>Adult Child Learning Disability Midwifery Social Work</td>
<td>Evaluate the impact of listening to digital patient stories</td>
<td>Qualitative Husserlian descriptive phenomenological approach, n=12 students, in-depth interviews (final year)</td>
<td>Although students articulated that they had learnt from their experiences, no action or reflection was included to illustrate this. Students reported helped them to understand alternative perspectives of care.</td>
<td>Single site Small sample Researcher involved in the intervention</td>
</tr>
<tr>
<td>Reitmaier, Davies; Reveling Smith; Mangan-Danckwart; Hongerhold; Klinkner (2014)</td>
<td>Adult nursing students</td>
<td>Explore ways in which visits with older adults contributed to nursing students’ understanding of ageing</td>
<td>Illuminative evaluation, semi-structured interviews with n=32 students (2 student cohorts) and analysis of 80 reflective journals</td>
<td>Identified mutual benefit of learning partnerships – repeated contact with older people. Reflective journals were part of assessment (graded) which may have impacted on students’ writing.</td>
<td>Single site (research conducted in one HEI) Researchers involved in intervention</td>
</tr>
<tr>
<td>Reitmaier Koehler, Davies; Smith; Hooks; Schanke, Loeffler; Carr; Ratziaff (2016)</td>
<td>Adult nursing students</td>
<td>Explore impact of learning partnership visits to older adults in the community</td>
<td>Quasi-experimental, pre- and post-test design. Data collected from three student cohorts 2012 (n=98), 2013 (n=80), 2014 (n=88) total (n=266) 85 % average response rate</td>
<td>Increased perception and preferences for working with older people.</td>
<td>Single site (Research conducted in one HEI) Researchers involved in the intervention</td>
</tr>
<tr>
<td>Last Name, First Name and Year</td>
<td>Study Type</td>
<td>Number of Participants</td>
<td>Methodology</td>
<td>Data Analysis</td>
<td>Findings</td>
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<tr>
<td>Ryan, Melby and Mitchell (2007)</td>
<td>Quantitative</td>
<td>Pre-test n=130 adult nursing students, Post-test (1 year later) n=94 adult nursing students</td>
<td>Kogan’s attitudes</td>
<td>SPSS</td>
<td>Students’ displayed more positive attitudes towards older people – results failed to reach statistically significant levels</td>
</tr>
<tr>
<td>Speed, Griffiths, Horne, Keeley (2012)</td>
<td>Qualitative</td>
<td>Service Users (n=38), Lecturers (n=23)</td>
<td>Thematic Analysis ATLAS used</td>
<td>Identified issues with involvement: Service users – lack preparation and support, issues regarding payment (not being paid appropriately, impact on benefits) Recommend more guidance regarding payment and support provided</td>
<td>Research conducted in one HEI, Student views not considered, Not clear relationship of researchers to participants</td>
</tr>
<tr>
<td>Torrance (2012)</td>
<td>Qualitative explorative study</td>
<td>Focus groups Purposive sample – n=19 lecturers across range of nursing specialities. NVIVO used to analyse data</td>
<td>Educator conflict - although supported benefits and necessary to involve SU’s, conflict regarding ‘using’ patients – need to explore ethical issues further</td>
<td>Researcher team relationship to participants not clear</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3: Participant Invite for Interviews

Date:

Dear Student

I am undertaking my Doctorate in Clinical Practice and am looking for volunteers to participate in my study on:

Impact of longitudinal visits to the homes of people with dementia and their carers: Adult student nurse perspectives.

The study will be conducted at University and will consist of:

Interviews:

Prior to your visit *(Time for Dementia visit with person with dementia and their carer)*

End of year 1

End of year 2

Prior to qualification – end of year 3

Follow up interview – 6 months post qualification

Each interview will last a maximum of 1 hour. Interviews will be audio recorded to ensure accuracy of transcription. Participants can request a copy of the audio recording and transcript.

You will also be asked to keep a reflective diary after each of your visits which will be analysed at the end of Year 1, Year 2 and Year 3.

Both the *Time for Dementia* and my PhD are funded by Health Education England Kent, Surrey, Sussex (HEKSS).

If you wish to participate and would like more information please contact:

Wendy Grosvenor

School of Health & Social Care

University of Surrey

Guildford, Surrey GU2 7TE

0148368297

w.grosvenor@surrey.ac.uk
Appendix 4: Consent Form for Interview and Reflective Journal

I, the undersigned, voluntarily agree to take part in the educational dementia research project

Please initial box if you agree with the above statement

I have read and understood the Information Sheet provided (version 4, 08/09/15). I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

Please initial box if you agree with the above statement

I agree to audio recording of interviews and sharing my reflective journal entries.

Please initial box if you agree with the above statement

I consent to my personal data, as outlined in the accompanying information sheet, being used for this study and the Time for Dementia research project. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).

Please initial box if you agree with the above statement

I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice. There will be no adverse effect on my studies or how I am treated by academic staff.

Please initial box if you agree with the above statement
I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Please initial box if you agree with the above statement

Name of volunteer (BLOCK CAPITALS) ...........................................................

Signed: ____________________________

Date: ____________________________

Name of researcher/person taking consent: WENDY GROSVENOR

Signed: ____________________________

Date: ____________________________
Appendix 5: Consent Form for Focus Group

I, the undersigned, voluntarily agree to take part in the educational dementia research project

Please initial box if you agree with the above statement

I have read and understood the Information Sheet provided (version 1, 20/05/16). I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

Please initial box if you agree with the above statement

I agree to audio recording of Focus Groups

Please initial box if you agree with the above statement

I consent to my personal data, as outlined in the accompanying information sheet, being used for this study and the Time for Dementia research project. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).

Please initial box if you agree with the above statement

I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice. There will be no adverse effect on my studies or how I am treated by academic staff.

Please initial box if you agree with the above statement
I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Please initial box if you agree with the above statement

Name of volunteer (BLOCK CAPITALS)  ..............................................................

Signed

Date

Name of researcher/person taking consent: WENDY GROSVENOR

Signed

Date
Appendix 6: Participant Information Sheet for Interview, Reflective Journal and Career Destination

(Version 4, 08/09/15)

Impact of longitudinal visits to the homes of people with dementia and their carers: Adult student nurse perspectives.

Introduction

My name is Wendy Grosvenor and I am a PhD student and a teaching fellow at the University of Surrey and I would like to invite you to take part in a research project. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish and feel free to contact me with any questions.

What is the purpose of the study?

This study seeks to explore the impact of the visits you are undertaking as part of the Time for Dementia programme on your career destination and your perception of the impact on your visits on your learning and professional development. Although this study is separate to the Time for Dementia study data may be used in the Time for Dementia report.

Why have I been invited to take part in the study?

You have been invited to take part in this study because you are an adult nursing student currently undertaking visits as part of the Time for Dementia programme.

Do I have to take part?

No, you do not have to participate in the research, taking part is entirely voluntary. It is up to you to decide whether you want to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you can withdraw at any time without giving a reason. Data up to the date of withdrawal may be used.

Choosing to either take part or not take part in this study will have no impact on your marks, assessments or future studies.

What will my involvement require?

You will be asked to attend 4 interviews which will last – each interview will take a maximum of 1 hour
Prior to your visit with a person with dementia and their carer

Year 1

Year 2

Year 3 – prior to qualification

Follow up contact (email) – 6 months post qualification (career destination)

All interviews will be audio recorded to ensure accuracy of data collection and transcription. Notes will also be taken by the researcher during the interview. You can request a copy of the audio recording and transcript or your interview

You will be asked to write a brief reflective journal summary after each of your visits – entries should be no more than 2 pages. Your journal entries will be analysed at the end using thematic analysis.

**Will my taking part in the study be kept confidential?**

Yes. All of the information you give will be anonymised so that those reading reports from the research will not know who has contributed to it. However, should you disclose that you or someone else is at risk then the researcher may need to report this to an appropriate authority. This would usually be discussed with you first.

Data generated in the course of the research will be kept securely in paper or electronic form for a minimum of ten years after completion of the project. Personal data will be handled in accordance with the Data Protection Act 1998.

**What will I have to do if I want to take part in the study?**

If you would like to take part in the study or would like to ask any further questions please email me at w.grosvenor@surrey.ac.uk. Taking part is voluntary.

**What are the possible disadvantages or risks of taking part?**

There are no identified physical risks to you participating in this research, the study will involve you donating some of your time to participate in focus group/interviews, questionnaires and completing reflective journals.

**What are the possible benefits of taking part?**

It is anticipated that this study will help contribute to future nurse curriculum development in how service users are involved in undergraduate nurse education. Understanding the career decisions of graduates is also an essential component of recruitment and retention strategies.

**What will happen to the results of the study?**

The results of the study will be presented as a thesis as part of fulfilment of a Doctorate. It is anticipated that the study will be published in healthcare journals in the future to highlight its findings and advance educational practice.
Who is organising and funding the research?

I am conducting this research as part of my Doctorate which I am studying at the University of Surrey. My Doctorate is funded by Health Education England, Kent, Surrey, Sussex as part of the larger Time for Dementia Project funding.

What if there is a problem?

Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact:

Wendy Grosvenor:
Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey | Guildford| Surrey |GU2 7XH
T:  +44 1483 682976
E:  w.grosvenor@surrey.ac.uk
Or
Supervisors:
Professor Ann Gallagher
Professor of Ethics and Care
School of Health Sciences
Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey | Guildford| Surrey |GU2 7XH
T:  +44 1483 689461
E:  a.gallager@surrey.ac.uk
Or
Professor Sube Banerjee, MBE
Professor of Dementia and Associate Dean
Brighton & Sussex Medical School,
Honorary Consultant Psychiatrist
Sussex Partnership NHS Foundation Trust
Trafford Centre for Medical Research,
Brighton & Sussex Medical School,
BN1 9RY
Or
Nora Kearney
Professor of Cancer Care and Head of School of Health Sciences
School of Health Sciences
Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey | Guildford| Surrey |GU2 7XH
T:  +44 1483 686693
E:  n.kearney@surrey.ac.uk
Who has reviewed the project?
The study has been reviewed and received a Favourable Ethical Opinion (FEO) from the University of Surrey Ethics Committee.
Appendix 7: Participant Information Sheet for Interview, Reflective Journal, Career Destination

(Version 5, 01/11/15)

Impact of longitudinal visits to the homes of people with dementia and their carers: Adult student nurse perspectives.

Introduction

My name is Wendy Grosvenor and I am a PhD student and a teaching fellow at the University of Surrey and I would like to invite you to take part in a research project. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish and feel free to contact me with any questions.

What is the purpose of the study?

This study seeks to explore the impact of the visits you are undertaking as part of the Time for Dementia programme on your career destination and your perception of the impact on your visits on your learning and professional development. Although this study is separate to the Time for Dementia study data may be used in the Time for Dementia report.

Why have I been invited to take part in the study?

You have been invited to take part in this study because you are an adult nursing student currently undertaking visits as part of the Time for Dementia programme.

Do I have to take part?

No, you do not have to participate in the research, taking part is entirely voluntary. It is up to you to decide whether you want to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you can withdraw at any time without giving a reason. Data up to the date of withdrawal may be used.

Choosing to either take part or not take part in this study will have no impact on your marks, assessments or future studies.

What will my involvement require?

You will be asked to attend 3 interviews which will last – each interview will take a maximum of 1 hour.
Year 1

Year 2

Year 3 – prior to qualification

Follow up email contact – 6 months post qualification (career destination)

All interviews will be audio recorded to ensure accuracy of data collection and transcription. Notes will also be taken by the researcher during the interview. You can request a copy of the audio recording and transcript or your interview

You will be asked to write a brief reflective journal summary after each of your visits – entries should be no more than 2 pages. Your journal entries will be analysed using thematic analysis.

**Will my taking part in the study be kept confidential?**

Yes. All of the information you give will be anonymised so that those reading reports from the research will not know who has contributed to it. However, should you disclose that you or someone else is at risk then the researcher may need to report this to an appropriate authority. This would usually be discussed with you first.

Data generated in the course of the research will be kept securely in paper or electronic form for a minimum of ten years after completion of the project. Personal data will be handled in accordance with the Data Protection Act 1998.

**What will I have to do if I want to take part in the study?**

If you would like to take part in the study or would like to ask any further questions please email me at w.grosvenor@surrey.ac.uk. Taking part is voluntary.

**What are the possible disadvantages or risks of taking part?**

There are no identified physical risks to you participating in this research, the study will involve you donating some of your time to participate in focus group/interviews, questionnaires and completing reflective journals.

**What are the possible benefits of taking part?**

It is anticipated that this study will help contribute to future nurse curriculum development in how service users are involved in undergraduate nurse education. Understanding the career decisions of graduates is also an essential component of recruitment and retention strategies.

**What will happen to the results of the study?**

The results of the study will be presented as a thesis as part of fulfilment of a Doctorate. It is anticipated that the study will be published in healthcare journals in the future to highlight its findings and advance educational practice.

**Who is organising and funding the research?**

I am conducting this research as part of my Doctorate which I am studying at the University of Surrey. My Doctorate is funded by Health Education England, Kent, Surrey, Sussex as part of the larger *Time for Dementia* Project funding.
What if there is a problem?
Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact:
Wendy Grosvenor:
Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey | Guildford| Surrey |GU2 7XH
T:  +44 1483 682976
E:  w.grosvenor@surrey.ac.uk
Or
Supervisors:
Professor Ann Gallagher
Professor of Ethics and Care
School of Health Sciences
Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey | Guildford| Surrey |GU2 7XH
T:  +44 1483 689461
E:  a.gallager@surrey.ac.uk
Or
Professor Sube Banerjee, MBE
Professor of Dementia and Associate Dean
Brighton & Sussex Medical School,
Honorary Consultant Psychiatrist
Sussex Partnership NHS Foundation Trust
Trafford Centre for Medical Research,
Brighton & Sussex Medical School,
BN1 9RY
Or
Melaine Coward
Head of School of Health Sciences
Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey | Guildford| Surrey |GU2 7XH
T:  +44 1483 682507
E:  m.coward@surrey.ac.uk
Who has reviewed the project?
The study has been reviewed and received a Favourable Ethical Opinion (FEO) from the University of Surrey Ethics Committee.
Appendix 8: Participant Information Sheet for Focus Groups and Career Destination

(Version 1, 20/05/16)

Impact of longitudinal visits to the homes of people with dementia and their carers: Adult student nurse perspectives.

Introduction

My name is Wendy Grosvenor and I am a PhD student and a teaching fellow at the University of Surrey and I would like to invite you to take part in a research project. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish and feel free to contact me with any questions.

What is the purpose of the study?

This study seeks to explore the impact of the visits you are undertaking as part of the Time for Dementia programme on your career destination and your perception of the impact on your visits on your learning and professional development. Although this study is separate to the Time for Dementia study data may be used in the Time for Dementia report.

Why have I been invited to take part in the study?

You have been invited to take part in this study because you are an adult nursing student currently undertaking visits as part of the Time for Dementia programme.

Do I have to take part?

No, you do not have to participate in the research, taking part is entirely voluntary. It is up to you to decide whether you want to take part. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part you can withdraw at any time without giving a reason. Data up to the date of withdrawal may be used.

Choosing to either take part or not take part in this study will have no impact on your marks, assessments or future studies.

What will my involvement require?

You will be asked to attend a focus group which will last approximately 45 minutes

Follow up postal questionnaire – 6 months post qualification
All focus groups will be audio recorded to ensure accuracy of data collection and transcription. Notes will also be taken by the researcher during the interview. You can request a copy of the audio recording and transcript or your focus group.

**Will my taking part in the study be kept confidential?**

Yes. All of the information you give will be anonymised so that those reading reports from the research will not know who has contributed to it. However, should you disclose that you or someone else is at risk then the researcher may need to report this to an appropriate authority. This would usually be discussed with you first.

Data generated in the course of the research will be kept securely in paper or electronic form for a minimum of ten years after completion of the project. Personal data will be handled in accordance with the Data Protection Act 1998.

**What will I have to do if I want to take part in the study?**

If you would like to take part in the study or would like to ask any further questions please email me at w.grosvenor@surrey.ac.uk. Taking part is voluntary.

**What are the possible disadvantages or risks of taking part?**

There are no identified physical risks to you participating in this research, the study will involve you donating some of your time to participate in focus group/interviews, questionnaires and completing reflective journals.

**What are the possible benefits of taking part?**

It is anticipated that this study will help contribute to future nurse curriculum development in how service users are involved in undergraduate nurse education. Understanding the career decisions of graduates is also an essential component of recruitment and retention strategies.

**What will happen to the results of the study?**

The results of the study will be presented as a thesis as part of fulfilment of a Doctorate. It is anticipated that the study will be published in healthcare journals in the future to highlight its findings and advance educational practice.

**Who is organising and funding the research?**

I am conducting this research as part of my Doctorate which I am studying at the University of Surrey. My Doctorate is funded by Health Education England, Kent, Surrey, Sussex as part of the larger Time for Dementia Project funding.

**What if there is a problem?**

Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact:

Wendy Grosvenor:
Faculty of Health and Medical Sciences
Duke of Kent Building
University of Surrey | Guildford | Surrey | GU2 7XH
Who has reviewed the project?
The study has been reviewed and received a Favourable Ethical Opinion (FEO) from the University of Surrey Ethics Committee.
### Appendix 9 Participant Visit Information

<table>
<thead>
<tr>
<th>Participant Ref number*</th>
<th>Total visits</th>
<th>Phase 1</th>
<th>Phase 2</th>
<th>Phase 3</th>
<th>Family visiting</th>
</tr>
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<tbody>
<tr>
<td>P1</td>
<td>9</td>
<td>4 visits</td>
<td>3 visits</td>
<td>2 visits</td>
<td>Same family</td>
</tr>
<tr>
<td>P2</td>
<td>10</td>
<td>5 visits</td>
<td>3 visits</td>
<td>2 visit</td>
<td>Same family</td>
</tr>
<tr>
<td>P3</td>
<td>6</td>
<td>6 visits</td>
<td><strong>Withdraw from study</strong></td>
<td><strong>Withdraw from study</strong></td>
<td>Same family</td>
</tr>
<tr>
<td>P4</td>
<td>9</td>
<td>4 visits</td>
<td>3 visits</td>
<td>2 visits</td>
<td>1 change**</td>
</tr>
<tr>
<td>P5</td>
<td>9</td>
<td>4 visits</td>
<td>3 visits</td>
<td>2 visits</td>
<td>1 change**</td>
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<tr>
<td>P6</td>
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<td>1 change**</td>
</tr>
<tr>
<td>P7</td>
<td>7</td>
<td>5 visits</td>
<td>2 visits</td>
<td><strong>Withdraw from study</strong></td>
<td>Same family</td>
</tr>
<tr>
<td>P8</td>
<td>9</td>
<td>4 visits</td>
<td>3 visits</td>
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<td>Same family</td>
</tr>
<tr>
<td>P9</td>
<td>4</td>
<td>4 visits</td>
<td><strong>Withdraw from study</strong></td>
<td><strong>Withdraw from study</strong></td>
<td>Same family</td>
</tr>
<tr>
<td>P10</td>
<td>4</td>
<td>4 visits</td>
<td><strong>Course Interrupt</strong></td>
<td><strong>Course Interrupt</strong></td>
<td>Same family</td>
</tr>
<tr>
<td>P11</td>
<td>9</td>
<td>3 visits</td>
<td>4 visits</td>
<td>2 visits</td>
<td>1 change**</td>
</tr>
<tr>
<td>P12</td>
<td>6</td>
<td>Delayed visits until end of Yr 1 as family withdrew</td>
<td>4 visits</td>
<td>2 visits</td>
<td>1 change**</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participant Ref number*</th>
<th>Total visits</th>
<th>Phase 1</th>
<th>Phase 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>FG13</td>
<td>7</td>
<td>5 visits</td>
<td>2 visits</td>
</tr>
<tr>
<td>FG14</td>
<td>7</td>
<td>4 visits</td>
<td>3 visits</td>
</tr>
<tr>
<td>FG15</td>
<td>8</td>
<td>5 visits</td>
<td>3 visits</td>
</tr>
<tr>
<td>FG16</td>
<td>8</td>
<td>5 visits</td>
<td>3 visits</td>
</tr>
<tr>
<td>FG17</td>
<td>7</td>
<td>4 visits</td>
<td>3 visits</td>
</tr>
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</table>

**Key:**
*Assigned to participants to assure anonymity
** Change of family in phase 2
<table>
<thead>
<tr>
<th>Participant Ref number*</th>
<th>Phase 1 Career destination</th>
<th>Phase 2 Career destination</th>
<th>Phase 3 Career destination</th>
<th>Phase 4 Career destination</th>
</tr>
</thead>
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<tr>
<td>1</td>
<td>Older people</td>
<td>Community</td>
<td>Community</td>
<td>Community</td>
</tr>
<tr>
<td>2</td>
<td>Undecided but probably Surgical</td>
<td>Undecided</td>
<td>Surgical</td>
<td>Surgical Rotation to consolidate practice (preceptorship programme)</td>
</tr>
<tr>
<td>3</td>
<td>Accident and Emergency</td>
<td>Withdrew from study</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Intensive Care Unit</td>
<td>Medical</td>
<td>Community</td>
<td>Practice Nurse working in Community to consolidate practice Would like to work in Accident and Emergency in the future</td>
</tr>
<tr>
<td>5</td>
<td>Older People</td>
<td>Undecided</td>
<td>Surgical</td>
<td>Surgical Rotation (preceptorship programme) Would like to work with Older Adults in the future</td>
</tr>
<tr>
<td>6</td>
<td>District Nursing</td>
<td>District Nursing, Community</td>
<td>Community</td>
<td>Community</td>
</tr>
<tr>
<td>7</td>
<td>Critical Care</td>
<td>Cath Lab/Coronary Care Unit</td>
<td>Withdrew from study</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Undecided – maybe Surgical</td>
<td>Older People</td>
<td>Acute</td>
<td>A&amp;E to consolidate practice To help prepare to work in Community</td>
</tr>
<tr>
<td>9</td>
<td>People with Dementia</td>
<td>Withdrew from study</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Respiratory</td>
<td>Course interrupt</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Medical</td>
<td>Medical</td>
<td>Medical then A&amp;E</td>
<td>Medical Rotation to consolidate practice and help prepare to work in A&amp;E (preceptorship programme)</td>
</tr>
<tr>
<td>12</td>
<td>Undecided</td>
<td>CCU Cardiology Department - high dependency,</td>
<td>Develop foundation skills on rotation placement then community</td>
<td>I.TU/HDU Surgical rotation to consolidate practice and help prepare skills to work in community (preceptorship programme)</td>
</tr>
</tbody>
</table>
Appendix 11: Development of Interview Prompts

Interview number:

Gender:

Age:

Prior experience of dementia – personal or professional

Can you tell me about your experiences of your visits with people with dementia and their carers in their homes?

Prompt points:

- Practice
- Learning
- Relationship
- Carer
- First career destination

Insights – dementia (added phase 2)

Uniform (added phase 2)

Relationships – yours and between person / carer (added phase 2)

Role of carer (added phase 2)

Dementia experiences in clinical practice (added phase 2)

Ending of visits/relationship (added phase 2)

Learning – how is this different? (added phase 2)

How does it feel listening to peoples' experiences (added phase 2)

Impact on practice (added phase 3)

Longitudinal contact – how feel (added phase 3)

View dementia? (added phase 3)

First post – destination (added phase 3)
Appendix 12: Topic Guide for Focus Group (Phase 2)

Gender:

Age:

Prior experience of dementia – personal or professional

Can you tell me about your experiences of your visits with people with dementia and their carers in their homes?

Prompt points:

• Uniform
• Changes - clinical practice? Examples…..
• Main learning
• Role of Care
• Changes to support
• Relationship
• End of visits
• First career destination
Appendix 13: Time for Dementia Summary of Measures

Participants will be asked to complete a series of quantitative measures on an annual basis. These will include measures of:

1. Alzheimer’s disease Knowledge Scale (ADKS; Carpenter et al., 2009) - a brief 30-item questionnaire designed to assess students’ knowledge of AD.

2. Dementia Knowledge Questionnaire (DK-20; Shanahan et al., 2013) - a brief 20-item questionnaire designed to assess dementia knowledge.

3. Approaches to Dementia Questionnaire (ADQ; Lintern et al., 2000) - a 19-item questionnaire designed to assess attitudes toward dementia patients.

4. Dementia Attitude Scale (DAS; O’Connor & McFadden, 2010) - a brief 20-item questionnaire designed to assess attitudes toward dementia.

5. Medical Condition Regard Scale (MCRS; Christison et al., 2002) - a brief measure of biases, attitudes and emotions in relation to specific medical conditions.


7. Student Satisfaction Survey - A questionnaire developed to assess students’ opinions about the LIC. The questionnaire is based upon the student evaluation form used in the Buddy Program (Mordhart, 2006). This measure will not be completed at baseline.

People with dementia and carers will complete a series of quantitative measures on an annual basis:

1. Standardized Mini-Mental State Examination

2. DEMQOL (Smith et al, 2005) – 28 item interviewer-administered questionnaire answered by the individual with dementia, dementia specific health related quality of life measure.

3. DEMQOL-Proxy (Smith et al, 2005) – 31 item interviewer-administered questionnaire answered by the caregiver on the individual with dementia, dementia specific health related quality of life measure.
4. Zarit Carer Burden Inventory (CBI; Zarit et al, 1985) – 22 item self-report questionnaire based on the original 29 item self-report questionnaire.

5. Patient Satisfaction Survey - A questionnaire developed to assess patients’ opinions about the LIC. The questionnaire is based upon the patient evaluation form used in the Buddy Program (Mordhart, 2006). This measure will not be completed at baseline.

6. Carer Satisfaction Survey - A questionnaire developed to assess carers’ opinions about the LIC. The questionnaire is based upon the carers evaluation form used in the Buddy Program (Mordhart, 2006). This measure will not be completed at baseline.

**Qualitative assessments:** A subset of patients, carers and students will complete a qualitative assessment on an annual basis. These will include:

1. Focus groups: to evaluate the impact of TFD on students, we will conduct focus group discussions each with medical students, nursing students and paramedic students. Each focus group will have 8-10 participants.

2. In-depth Individual Interviews: will be used to access the experiences of those who have taken part in TFD. The number of interviews will be determined by the point at which no new themes emerge via thematic analysis however we estimate this to be around 20 interviews for each of the four groups; (1) medical students, (2) nursing students, (3) people with dementia and (4) family carers.
Appendix 14: Reflective Diary Prompts

Description:
• Briefly describe what happened during your visit.

Feelings:
• How were you feeling before the visit?
• What is the most important emotion or feeling you had about your visit?

Evaluation:
• What was good about the visit?
• What was bad?
• What was easy?
• What was difficult?
• What went well?
• What did you do well?

Analysis:
• What could you have done differently?
• What have you learned from your visit?

Action Plan:
• How can you use the lessons learned from this visit in future visits?
• Can you apply what you have learnt from your visit in practice?
• What will you do for your next visit?
Appendix 15: Ethical Approval

14 September 2015

Dear Mrs Grosvenor

UCE ref: UEC/2015/082/PHIVS
Study Title: Non-clinical practice placement visits with people with dementia and their carers: Adult student nurse perspectives

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 14 September 2015

The final list of documents reviewed by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cover letter from researcher in response to queries from the UEC, sent 17 Aug 2015</td>
<td>09 Sept 2015</td>
<td></td>
</tr>
<tr>
<td>Email from researcher In response to queries from RIGO, sent 20 Jul 2015</td>
<td>29 Jul 2015</td>
<td></td>
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<tr>
<td>Ethics Application Form - tracked copy</td>
<td>Submitted</td>
<td>09 Sept 2015</td>
</tr>
<tr>
<td>Protocol - tracked copy</td>
<td>4</td>
<td>08 Sept 2015</td>
</tr>
<tr>
<td>Appendix 1: Consent form for pre-registration student nurses - tracked copy</td>
<td>4</td>
<td>08 Sept 2015</td>
</tr>
<tr>
<td>Appendix 2: Participant Information Sheet - tracked copy</td>
<td>4</td>
<td>08 Sept 2015</td>
</tr>
<tr>
<td>Appendix 3: Semi-structured interview questions - tracked copy</td>
<td>4</td>
<td>08 Sept 2015</td>
</tr>
<tr>
<td>Appendix 4: Time for Dementia Summary of Measures</td>
<td>4</td>
<td>08 Sept 2015</td>
</tr>
<tr>
<td>Appendix 5: Time line</td>
<td>4</td>
<td>08 Sept 2015</td>
</tr>
<tr>
<td>Recruitment letter</td>
<td>2</td>
<td>08 Sept 2015</td>
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<tr>
<td>Research Insurance Proforma</td>
<td>2</td>
<td>08 Sept 2015</td>
</tr>
<tr>
<td>Public Liability insurance Certificate</td>
<td></td>
<td>21 Jul 2015</td>
</tr>
</tbody>
</table>
This opinion is given on the understanding that you will comply with the University’s Ethical Principles & Procedures for Teaching and Research.

If the project includes distribution of a survey or questionnaire to members of the University community, researchers are asked to include a statement advising that the project has been reviewed by the University’s Ethics Committee.

If you wish to make any amendments to your protocol please address your request to the Secretary of the Ethics Committee and attach any revised documentation.

The Committee will need to be notified of adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons. Please be advised that the Ethics Committee is able to audit research to ensure that researchers are abiding by the University requirements and guidelines.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

[Signature]

Dr Sophie Wehrens
Research Integrity and Governance Officer, Research & Enterprise Support

cc. Professor Ann Gallagher, School of Health Sciences, FHMS
Appendix 16: Public Liability Assurance

To Whom It May Concern

Our ref: SG/IND 21 July, 2015

Zurich Municipal Customer: University of Surrey and wholly-owned Subsidiary Companies

This is to confirm that University of Surrey and wholly-owned Subsidiary Companies have in force with this Company until the policy expiry on 31 July 2016 Insurance incorporating the following essential features:

Policy Number: NHE-17CA01-0013

Limit of Indemnity:
Public Liability: £ 35,000,000 any one event
Products Liability: £ 35,000,000 for all claims in the aggregate during any one period of insurance
Pollution: any one event inclusive of costs
Employers’ Liability: £ 35,000,000

Excess:
Public Liability/Products Liability/Pollution: £ 250 any one event
Employers’ Liability: Nil any one claim

Indemnity to Principals:
Covers include a standard Indemnity to Principals Clause in respect of contractual obligations.

Full Policy:
The policy documents should be referred to for details of full cover.

Yours faithfully

[Signature]

Underwriting Services
Zurich Municipal
Farnborough
Appendix 17: Focused Coding to Support Development of Categories

<table>
<thead>
<tr>
<th>Excerpt from Interview with P12: phase 3</th>
<th>Initial Codes</th>
<th>Conceptual category</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Our practice it's heavily task-based</strong>, whereas Time for Dementia you have the <strong>time</strong>, you make the <strong>time</strong>, and I feel that they really <strong>appreciate the opportunity</strong> to discuss things. It has enabled us to build relationships with them over <strong>time</strong>. Felt good to be part of their lives.**</td>
<td>Task-based care&lt;br&gt;Time&lt;br&gt;Reciprocal&lt;br&gt;Build relationships&lt;br&gt;Time&lt;br&gt;Felt good to be part of lives</td>
<td>Therapeutic relationship</td>
</tr>
<tr>
<td><strong>Do you think it's changed your perception of how dementia impacts on the person and their family in any way?</strong></td>
<td>Taboo&lt;br&gt;Slow down&lt;br&gt;Misconceptions&lt;br&gt;Better understanding&lt;br&gt;Dementia as a whole&lt;br&gt;Seeing dementia&lt;br&gt;Different perspectives</td>
<td>See dementia as a whole&lt;br&gt;New Ways of Seeing</td>
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<td><strong>And do you think it's changed your practice?</strong></td>
<td>Patient is very important&lt;br&gt;Importance of family&lt;br&gt;Saw the bigger picture&lt;br&gt;Challenge to manage&lt;br&gt;See&lt;br&gt;Whole journey</td>
<td>Person centred care&lt;br&gt;New ways of seeing&lt;br&gt;See dementia as a whole</td>
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<tr>
<td><strong>Has it impacted on your confidence?</strong></td>
<td>Increased confidence</td>
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<tr>
<th>Task-based care&lt;br&gt;Time&lt;br&gt;Reciprocal&lt;br&gt;Build relationships&lt;br&gt;Time&lt;br&gt;Felt good to be part of lives</th>
<th>Taboo&lt;br&gt;Slow down&lt;br&gt;Misconceptions&lt;br&gt;Better understanding&lt;br&gt;Dementia as a whole&lt;br&gt;Seeing dementia&lt;br&gt;Different perspectives</th>
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<tr>
<td><strong>I firmly believe that there should be less <strong>taboo</strong> around the subject, like I feel that that's the direction we're going to head is that families are more open to discussion about it, and I think programmes such as Time for Dementia gives the opportunity to <strong>slowly face</strong> out the <strong>misconceptions</strong> about it and gives the next generation of healthcare professionals a <strong>better understanding</strong> of how to go about approaching dementia as a whole, seeing dementia from different perspectives.</strong></td>
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<td><strong>And do you think it's changed your practice?</strong></td>
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<tr>
<td><strong>I believe so. I mean care planning is everything and yes, the <strong>patient is very important</strong> but <strong>so is their family</strong> and what support are there available after the setting that you've basically discharged them from. I <strong>saw the bigger picture</strong> of it, it's quite a <strong>challenge</strong> for our healthcare, Health and Social Care systems to <strong>manage</strong>, but yeah, I do what I can to make sure that a patient living with dementia has the right support. <strong>See the whole journey.</strong></strong></td>
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<td><strong>Has it impacted on your confidence?</strong></td>
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<tr>
<td><strong>I believe so. I have most definitely <strong>increased confidence</strong> in talking to people and their relatives, especially the relatives. Before this programme, I</strong></td>
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only knew how to interact with the patient with dementia themselves, but after seeing them outside of a clinical setting in their own home, you see them as individuals more so. I know you see them as individuals in the care setting they are under, but at home sometimes they can be very different and that interaction with their loved ones, carers, it's totally different I'd say.

Yeah I believe so, increased my confidence a lot actually. As a, one of the more youngish student nurses like I always feel that I don't have enough life experience to know what I'm on about, and it's usually just the clinical knowledge base that I have. But in actual fact I can bring things that I have experienced in my life and it's the little things that make a difference.

It’s gaining awareness of the differences in the roles of people, the couple we visit have disclosed that it has affected their relationship. There are role shifts, privilege to actually see and hear changes over time...valuable and unique.

Visits, I feel immersed in their history...there’s more to the person than just the label, see the person and not just dementia

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<thead>
<tr>
<th>See them as individuals</th>
<th>Interactions with their loved ones, it's totally different</th>
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<tr>
<td>Increased confidence</td>
<td>Life experience</td>
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<tr>
<td>Clinical knowledge</td>
<td>It’s the little things</td>
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<td>Making a difference</td>
<td>Roles</td>
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<td>Role shifts</td>
<td>Privilege to actually see and hear</td>
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<tr>
<td>Valuable and unique</td>
<td>Valuing relationships</td>
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<tr>
<td>Sharing their lives</td>
<td>Humanising dementia</td>
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<td>Labelling</td>
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<td>See the person</td>
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Appendix 18

Memo: Phase 1 Interview (Participant 1)

Prior to our interview I checked I had all the equipment and paperwork I needed for the interview. As it was my first interview I acknowledged that I felt very nervous about preparation of both the equipment as well as how equipped I was to interview. I had never had to use a Dictaphone before this and had to spend time getting familiar with the equipment. My anxiety of equipment malfunction made me anxious throughout the interview and I was conscious that I kept checking to ensure it was still recording so my attention was distracted from the participant at times and what she was saying. Despite being an experienced health care practitioner and working in education for the last 3 years I felt completely out of my comfort zone. I also acknowledge that the impact of being a researcher as well as a tutor working in the institution significantly increased my anxiety to produce a credible standard in my research approach and interviewing. I acknowledge that I can be very self-critical and this has been an inhibitory factor in the past. I realise that I underestimated the transition process from being a tutor to starting to do research – it is like learning a new language. I identified that I needed to explore and identify throughout the process of what I need to learn whilst planning how to get there, it is a constant spiral of going forward but also backwards as the more I learn the more I realise I needed to go back over previous writings. I had progressed from detached observer of the research process to involved performer.

I was conscious throughout the interview of not wanting to influence the participant’s responses during the interview however on reflection I felt this inhibited me as there were many missed opportunities identified on reflection and listening to the tape to explore and clarify what the participant said. At the end of our interview I turned the recording device off however in hindsight this was a mistake as we continued talking about her experiences and I had to make notes of what was said.

She talked about the emotional impact the visit had on her – of stepping in their shoes for a moment. She was clearly touched by the contact, gaining insight into dementia which she had no previous personal context of – it gave meaning to the experience of dementia. She talked of how she associated the experience of what she heard with her own family and the impact on them. I felt emotional listening to her accounts of her visits and it was a real privilege to listen and gain an insight into some of her perceptions of her experiences.
Writing the memo after the interview made me appreciate how much I had learnt from the interview, helping me to develop ideas to explore in future interviews. One of the areas identified that I would like to explore further was if students had thought about ending their relationships. This topic came from this interview as she spoke in depth about the close relationship she had developed with the couple however this had made anticipate ending the relationship. Exploring ending relationships was something that I added to the interview guide in future interviews.
Appendix 19

Memo Phase 1 Interview (Participant 7)

As the interview progressed, P7 shared how she did not really see the point of the visits. She had minimal experience of dementia prior to the visits working in an independent assisted living home for older adults and some of her experiences in clinical practice involving people with dementia had been difficult. She spoke using terms such as difficult and challenging. She spoke of the difficulties she had experienced in trying to care for people with dementia on the ward, she felt that if their behaviour was challenging that they should be cared for in a dementia unit. Despite being quite negative about her experiences in practice placements and not really seeing the point of the visits later in the same interview she shared an example of how she had advocated for a person with dementia. She shared that she had started to read ‘This is Me’ more as a result of her experiences of the TfD visits to try and find out a bit more about the person with dementia. This enabled her to advocate for a person with dementia to move to a quieter area away from the nurse’s station as she observed that the person was agitated by noise (she read that noise upset her in ‘This is Me’).

It was interesting that although she spoke about not understanding the point of the visits she shared an example of being proactive in her actions to advocate for someone with dementia. As a result of her visits there appeared to be an increased understanding about the person resulting in her using ‘This is Me’ when in practice. This clearly made the student reflect on the need to use written tools such as personalised information booklets for people with dementia, to help to connect with the person.
Appendix 20

Example of Conceptual Memo

Embracing + Developing + Challenging = Adapting?

Embracing new ways of seeing dementia was slowly incorporated into practice as participants shared how their practice had developed as a result of their visits. This evolving process involved feelings such as anxiety and confidence. Participants talked about learning and adapting their practice to bring positive changes to their development as well as improving care for people with dementia. They realised that there were many benefits to their own professional development as well as benefits for the person with dementia.
Appendix 21: Time Line
Appendix 22: Poster Presentation, University of Surrey: Awarded First Prize (April 2015)

Sharing Lives and Changing Practice

Partnership Education: Learning WITH people with dementia
Preparing student nurses for the future

Dementia – Health and Social Care Issues

Dementia is a growing, global challenge, with the number of people living with dementia worldwide estimated at 44 million people – a figure set to double by 2030. In England, it is estimated that around 850,000 people have dementia. Dementia takes a huge toll on our health and care services, costing society an estimated £26 billion a year, more than the costs of cancer, heart disease or strokes. With the number of people with dementia expected to double in the next 30 years and predicted costs likely to treble to over £50 billion, we are facing one of the biggest global health and social care challenges - a challenge as large as those posed by cancer, heart disease and HIV/AIDS. Kent, Surrey and Sussex have the greatest proportion of older people in the country, with 50,000 people currently diagnosed with dementia in the region. This figure is expected to rise to 75,000 by 2030.

Intervention: Learning WITH people with dementia.

Innovative partnership education programme developed to overcome the limitation of current block clinical placements which emphasise acute care and crisis.

Student nurses (adult branch) will visit people with dementia and their carers in their homes every 3 months during Year 1 and Year 2 of their training.

This ground breaking education initiative will provide students with a unique insight into the experiences of living with dementia to help understand what life is like living with dementia.

Research Aims:
- Explore the impact of providing student nurses with longitudinal experience of dementia on empathy
- Investigate the impact of partnership education on career destination
- Explore social issues surrounding how students learn WITH rather than ABOUT people with dementia

Methods:
- Mixed method longitudinal study – Intervention and Control Group
- Measurements taken: Pre-intervention; Year 1, 2, 3
- Exploratory interviews
- Reflective journals
- Career destination questionnaires (replicated study)

Potential impact of the intervention:
- Develop better understanding of the lived experience of dementia to improve quality of care
- Positive impact on empathy – current evidence highlights empathy may reduce from year 2 of training
- Impact positively on future career choices – current evidence shows us that working with older people and dementia is not a career choice for many students when they qualify
- Partnership education model could be applied to any long term condition

Nursing is an art and a science. By promoting scientific inquiry into empathy and translating it into evidence-based practice, we leverage the science of nursing to substantiate the art of nursing and ultimately elevate its practice.

Wendy Grosvenor, School of Health Sciences

Dementia – See ME

Supervisors: Professor of Ethics and Care Ann Gallagher, Professor Subha Banerjee
Time for Dementia project and PhD funded by Health Education England, Kent, Surrey and Sussex
Appendix 23: Training Undertaken

<table>
<thead>
<tr>
<th>Training Undertaken</th>
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<tbody>
<tr>
<td>Core Writing Skills: Writing Coherently</td>
<td>17/10/14</td>
</tr>
<tr>
<td>Core Writing Skills: Writing Critically</td>
<td>31/10/14</td>
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<tr>
<td>Getting Published</td>
<td>04/11/14</td>
</tr>
<tr>
<td>Welcome to your PhD</td>
<td>12/11/14</td>
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<tr>
<td>Refworks and RefAware</td>
<td>12/12/14</td>
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<td>Poster Presentation</td>
<td>06/03/15</td>
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<tr>
<td>Confirmation Process</td>
<td>04/05/16</td>
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<tr>
<td>Qualitative Interviewing</td>
<td>20/06/16</td>
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<td>Conducting a Systematic Review</td>
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<td>Writing Retreat</td>
<td>02/07/16</td>
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<td>NVivo Training</td>
<td>01/11/17 - 02/11/17</td>
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<td>Advanced NVivo Training</td>
<td>08/12/17</td>
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<tr>
<td>Viva Preparation</td>
<td>24.09.18</td>
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Dissemination of the Research Project

April 2015 I presented a poster: *Sharing Lives and Changing Practice*, at the University of Surrey Post Graduate Research Conference winning first prize (Appendix 22).

May 2017 I presented for 30 minutes at the Royal College of Nursing International Research conference in Oxford: *New Ways of Seeing: Adult nursing perspectives on the value of longitudinal home visits to people with dementia*