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# **What is the meaning of family-centred Admiral Nursing for carers?**

**PENELOPE ANN HIBBERD**

**PhD**

**2011**

# **What is the meaning of family-centred Admiral Nursing for carers?**

**PENELOPE ANN HIBBERD**

A thesis submitted in partial fulfilment  
of the requirements of the  
University of Northumbria at Newcastle  
for the degree of  
Doctor of Philosophy

Research undertaken in the School of Health,  
Community and Education Studies

**March 2011**

## **Abstract**

Admiral Nurses are mental health nurses specialising in supporting family carers of people with dementia in community and other settings. Working collaboratively with other professionals, Admiral Nurses seek to improve the quality of life for people with dementia by focusing on supportive interventions for family carers. However, to date, there has been limited attention paid to elicit the meaning of such supportive interventions as constructed by family carers of people with dementia on the receiving end of such services. This thesis aims to address this imbalance by operationalising an appreciative inquiry 4 ‘D’ cycle [discovery, dream, design and destiny] informed by a preliminary stage questionnaire distributed to the whole population of Admiral Nurses in the United Kingdom (n=54) to contextualise current practice. Appreciative inquiry is a research method which explores experiences of services by eliciting accounts of good practice as a foundation for analysis and development.

The data from the questionnaire identified constructs of respect, empowerment, negotiation and partnership working with carers that was compared with the literature from the family-centred literature. The empirical indicators of carer ability and competence were articulated as, decision making, information receiving and sharing. The interview questions for the ‘discovery’ stage of the 4 ‘D’ cycle were crafted from these emerging themes.

Using an appreciative inquiry 4 ‘D’ cycle data were then collected over a nine month period. The ‘discovery’ phase also included the voluntary participation of nine carers. Telephone interviews were used to elicit stories of value and well-being of caring for a person with dementia. Alongside this data collection method, participation was invited from fifty four Admiral Nurses, two carer’s and people with dementia peer support groups and stakeholders

of the Admiral Nurse Service i.e. service managers, administration staff and support staff from *for dementia*. The resultant focus group used mind mapping to capture caring relationships and steer subsequent data collection. These data were further analysed using a constant comparison technique before moving in to the ‘dream’ stage of the 4 ‘D’ cycle. The ‘dream’ stage gave an opportunity for creative study methods. The carer group participated in data collection using photography and narrative whilst the Admiral Nurse, carer, person with dementia and stakeholder group attended a further focus group using an adapted nominal technique. During the ‘design’ stage of the 4 ‘D’ cycle a focus group was held for both groups. Themes were further analysed using a constant comparison technique moving the inquiry into the ‘destiny’ stage. The carer data revealed the unique way that each carer managed their relationships within a complex and at times very stressful caring situation. Although each carer developed their caring role within sometimes difficult environmental, practical and emotional constraints they developed strategies and coping mechanisms that enabled them to continue to care for the person with dementia. A reference group of nine carers and two Admiral Nurses provided consultation, rigour and guidance to the study throughout the data collection period.

The findings were expressed through four typologies of caring relationships, themed as recognising (1), transforming (2), stabilising (3) and moving on (4). In this context, carers developed feelings of wellbeing and value of their caring role, re-shaping their feelings of self. This is an alternative to the manifestation of isolation, stress and burden as an outcome of a caring role. Secondly, the co-construction of four principles themed as attributes (1), meeting the needs of the carer (2), knowledge and skills (3) working with organisations (4) deploying underlying values (e.g. trust, flexibility, honesty, accessibility, knowledge and continuity) of

Admiral Nurse practice have developed an understanding of a family-centred approach to Admiral Nursing that is relationship focused.

Implications for practice were that carer's expressed wish is to be recognised as individuals. There is a complex interaction between the carer and the person with dementia and the people that support them which has a powerful influence on how the caring role is supported and maintained. This is represented by the conceptual model that has been developed in this study to present how Admiral Nursing principles and values support that caring role.

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## **Preface**

### **Admiral Nursing: A Study Context**

The thesis presents evidence from the experiences of carers, people with dementia, Admiral Nurses and other stakeholders who have all had contact with an Admiral Nurse, either through their caring experience or as a stakeholder in an Admiral Nurse Service. The Admiral Nursing Service was introduced in the early 1990s as a direct result of consultation with family carers of people with dementia and is primarily aimed at supporting family carers. Admiral Nurses are all registered mental health nurses who practice in a range of primary, secondary and tertiary services and are employed by the NHS. The name Admiral Nurse is adopted from the gentleman whose family founded the service for carers of people with dementia; his name was Joseph Levy, nicknamed ‘Admiral Joe’ as he was a keen sailor in his spare time. Until his death, Admiral Joe lived with vascular dementia and was cared for at home by his wife and family in North London.

The charity *for dementia* (previously The Dementia Relief Trust) was formed to support the Admiral Nurse Service in 1990 and remains the central organisation to the service. *for dementia* provides an organisational structure to help support the work of Admiral Nurses, for instance in governance for the service and supporting finance for new services with a host organisation, as well as funding monthly peer group supervision and practice development for existing Admiral Nurses wherever their location. This supportive process is managed by an Admiral Nurse Practice Development Lead located at the central coordinating office in London. There are currently 54 Admiral Nurses in England and Wales and, at time of writing, Admiral Nurses are located in patches across London, Kent, the West Midlands, the North

West of England and Flintshire. All Admiral Nurses are hosted by NHS Trusts and the supportive arm of the charity *for dementia* provides an innovative way of facilitating Admiral Nurses to work collaboratively and across organisational boundaries. *for dementia* provides the supportive ‘brand’ of Admiral Nursing ensuring a consistent and valued resource of practice development and group supervision; this facilitates the Admiral Nurse service to work in partnership with family carers (Casey 1995).

As an intervention approach, the Admiral Nurse Service currently utilise the stress-burden model described by Zarit *et. al.* (1982, 1985, 1987) and Pearlin *et. al.* (1990) as its underpinning philosophy and interventionist approach.

In their day-to-day practice Admiral Nurses:

- Work with family carers and people with dementia, with family carers as the prime focus of their intervention;
- Work with family carers and people with dementia to provide practical advice, emotional support and information. They use psychosocial skills to educate and support the management of the care of a person with dementia;
- Deliver education and training in dementia care and carer’s needs;
- Make available consultancy to professionals working with people with dementia and their families; and
- Promote best practice in person-centred dementia care.

(DH 1990; DH 1999a, b; DH 2000; DH 2001; DH 2004; DH 2006).

Referrals to the Admiral Nurse Service are often complex requiring expertise in working with family relationships as well as advanced skills in dementia care (Keady *et. al.* 2007a). The Admiral Nurse service is unusual in that it provides a health care intervention for carers and families by taking into account the needs of the person with dementia. With twenty years of accumulated practice experience, the Admiral Nurse service has recognised that the needs of carers and families are constantly evolving and changing with the accompanying challenge of balancing the needs of the carer and the person with dementia in the context of a relationship (Keady *et. al.* 2004, Nolan *et. al.* 2004, Adams 2005). Admiral Nurses are also aware of the nursing knowledge required to provide the care to carers of people with dementia but have struggled to find an existing model that provides a framework (UKCC 1999, Dewing & Traynor 2005, O'Connor 2006). Having the knowledge and skills to support this journey is often trivialised and ignored by health and social care professionals. As an Admiral Nurse I have been privileged by being able to listen to carers relate their personal stories of their caring journey. Each case has its own very complex set of issues, concerns and problems supported by the skill and knowledge of the carer (Hibberd *et. al.* 2008).

The origins of this thesis start with my reflections of my personal life, career in nursing and questions I had about the meaning of nursing older people with dementia and their families. This thesis will explore this question and suggest areas of family-centred development.

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## **Acknowledgements**

Undertaking this study would not have been possible without the support and participation of many people and I would like to express my thanks to family, friends and colleagues who accompanied me on my journey through the research process that has resulted in this thesis. To identify everyone individually is not possible, nor appropriate as it will breach confidentiality. To them I express my deepest thanks and appreciation.

There are a few people who made personal sacrifices to enable me to accomplish this work and for this reason I would like to acknowledge their specific contribution. Firstly my husband Tony, and my children Clare, Louise and Laura, who have accepted my absences from home to plan, study and collect data and write over the last four years. To them I am grateful and express my love for their understanding and patience. I would also like to express my thanks to my supervision team Professor Jan Reed, Professor John Keady and Professor Bill Lemmer, who have given their expert advice and unfailing support and encouragement to complete this thesis. Finally the nine carers and all the carers, people with dementia, Admiral Nurses and stakeholders who freely gave their time to tell their stories and construct the principles and values of the Admiral Nurse. Each person's time is precious and I valued the opportunity to be with them and learn about their experiences. In writing this thesis I have aspired to be true to the stories that they told and reflect its presented meaning.

## **Declaration**

I declare that the work contained in this thesis has not been submitted for any other award and  
that it is my own work.

Name: Penelope Ann Hibberd

Signature:

Date: 14<sup>th</sup> March 2011

## **Structuring the thesis**

### ***Referencing:***

- More than two authors are referenced in the text as lead author *et.al.*
- More than one reference by the same author is listed in chronological order.
- Two or more of the same year by the same author references consecutively as date b  
(e.g.1999b)

Narrative Cohesion: us of 'I'

For ease of narrative cohesion, from chapter 1 onwards the personal pronoun 'I' will be used when discussing the author's contribution to the research act as it provides a level of reflexivity and engagement that is aspired to, both in the presentation of the thesis and also in clinical work as an Admiral Nurse. It is important, in my opinion, to keep the human and relational aspects of the thesis and writing to the fore.

### ***Abbreviations:***

Community Psychiatric Nurse ..... CPN

Department of Health..... DH

Department of Health and Social Security..... DHSS

General Practitioner ..... G.P.

National Health Service..... NHS

National Service Framework..... NSF

United Kingdom..... UK

i.e. ..... that is

e.g. ..... for example

## ***Introduction***

Dementia care, has its origins in a bio-medical model. However over the past thirty years it has grown to develop an inclusive and psycho-social approach based on concepts of individualised care, person-centred care and relationship centred care (Kitwood 1997; Clarke 1999; Nolan et al., 2006; Keady *et. al.* 2007a). Service user and carer involvement are also now prominent in the literature with policy documents to guide these inclusions (DH 1999a, b; DH 2000; DH 2001; DH 2004; DH 2005a, b; DH 2009). Services are being actively encouraged to develop and implement inclusive approaches to the needs of carers of people with dementia from their perspective.

In the thesis, I will argue that central to the process of caring are the individual experiences of carers who identify periods of well-being and value to how they manage and develop their relationships with the person with dementia. At the same time, I will identify how the principles and values of Admiral Nursing underpin a family-centred approach for working in partnership with carers, people with dementia and associated services to support and develop the typology of caring relationships along the caring trajectory. The thesis will follow a chronological approach; with the context of the study, the literature review, methodology and study design chapters cover the period up until October 2007 when I first engaged in the initial fieldwork.

The thesis comprises a series of chapters, as follows:

## **Chapter 1: A Personal Reflection**

This reflexive account addresses my decision to undertake the research examining my early adjustment to nursing people with dementia and how it has become rooted in my identity, and includes personal as well as professional experiences (Higgs and Titchen 2001). The narrative is arranged in chronological order and describes my early years and later my experiences as a nurse. The chapter aims to give insight into the reasons for me beginning this research journey.

## **Chapter 2: Dementia a Contextual Description**

This chapter reviews the literature in relation to dementia to briefly outline different models of dementia and biomedical, psychosocial and relational approaches to the care of people with dementia. The chapter begins with an exploration of the key policy considerations and the context of the demography of dementia in the UK. In keeping with the primary focus of the study the chapter concludes by setting the context of a caring role in dementia care, and the context of community psychiatric nursing and the development of Admiral Nursing in the 1990s.

## **Chapter 3: A Family-centred Care: approach a Literature Review**

This chapter provides a review of family-centred care approaches up until September 2006 to enable the progression of ethical approval and data collection. However, the literature was continually checked and updated throughout the study and the updates are reflected in Chapters 7 and 8. The chapter begins by examining the psychosocial intervention literature in relation to the meaning it holds for carers. The chapter then describes a family-centred approach drawing on literature from mental health nursing, models of nursing, children's nursing and palliative care. The summary discusses how the literature contextualises the

inquiry with the literature from chapters one and two, and the anecdotal evidence from the Admiral Nursing service to explore the meaning of family-centred Admiral Nursing to carers.

## **Chapter 4: Methodology**

This chapter gives a brief overview of the philosophical background using a ‘Freirean’ approach describing the participation of ‘people’ at a ‘grass roots’ level to enable an awareness of and engagement with their world. The chapter goes on to describe the development of the research methodology used in this thesis underpinning my reflexive approach to writing this thesis. This resulted in the choice of appreciative inquiry as a research methodology which focuses on exploring strengths in the development of theory and practice. How appreciative inquiry works as a research methodology is described as is the 4 ‘D’ cycle of appreciative inquiry which structures data collection and analysis. This is followed by an outline of methodology with supporting rationale for each of the study methods, telephone interviews, focus groups, photography with narrative, mind mapping and an adapted nominal group technique. The chapter concludes with a description of the development of a constant comparative technique as the analytic framework for this thesis.

## **Chapter 5: Study Methods**

This chapter considers the details of study design based on the principles described Chapters 2, 3 and 4, including research ethics, strategies of sampling, a discussion on participation, recruitment, and the process of obtaining consent. The chapter then describes the participatory nature of the research design, its phases and the use of appreciative inquiry. The chapter continues with an explanation the analytic methods and the interpretation of the data. The chapter concludes with a description of how the data were managed.

## **Chapter 6: Discovery, Dream and Design**

This chapter begins with the contextualisation of current Admiral Nurse practice in the preliminary stage using a questionnaire to Admiral Nurses n=54. The chapter is then divided into three subsections to reflect the journey through the first three stages of the appreciative inquiry 4 ‘D’ cycle, discovery, dream, and design. The discovery phase of the 4 ‘D’ cycle starts with my role as the researcher and then a description of the narrative data from the carers’ telephone interviews and from focus group 1 which used mind mapping as a primary data collection method. The data were co-constructed with participants and reference groups to develop the questions for the dream phase of the 4 ‘D’ cycle used to structure data collection. The dream stage develops the co-construction of carer ‘caring relationships’ and Admiral Nurse principles and values. The dream phase of the 4 ‘D’ cycle magnified the ‘positive core’ by imagining and building upon the existing values generated in the discovery stage. The data collection continues in this chapter using photography with narrative and focus groups using an adapted nominal group technique. The data collection is described using the co-constructed themes, principles and values developing an early model of supporting carers, a typology of caring relationships and the further development of Admiral Nurse principles and values. Using an appreciative inquiry approach, the third stage of data collection described in this thesis is design. Here, the chapter provides a description of data collection inviting study participants to two separate facilitated focus groups. The carer participants were invited to a focus group to view the data and agree provocative propositions. The second focus group comprised of members of the carer, people with dementia, Admiral Nurse and stakeholder participants. The chapter concludes with co-constructed data ready to develop a theoretical understanding of the typology of caring relationships and the principles and values of Admiral Nursing, as described more fully in the next chapter.

## **Chapter 7: Destiny - Completing the Appreciative Inquiry Cycle**

This chapter is the description of the last stage of the appreciative inquiry 4 ‘D’ cycle, destiny or ‘delivery.’ The destiny stage develops the theoretical understanding of the co-constructed data attempting to add to the debate about how Admiral Nurses can support a carer of a person with dementia. The model is the result of the implementation of appreciative inquiry theory developed by the participants from their development of the typology of caring relationships and the principles and values of Admiral Nursing. The chapter describes the emergence of a model that supports how Admiral Nurses can work using a family-centred approach throughout the caring trajectory.

## **Chapter 8: Reflections on the Research Journey**

The final chapter in this thesis discusses how a carer develops their caring role using the typology of caring relationships which provides a framework of practice for the Admiral Nurse. The practice implications of the Admiral Nurse are discussed in context of the four principles and underlying values that have been identified in this inquiry. The chapter concludes with a reflection of the use of appreciative inquiry as a methodology and my journey as a researcher.

# **Chapter 1**

## **A Personal Reflection**

I approached the PhD as a neophyte researcher who was steeped in practice and educational knowledge of dementia care but with limited exposure to research methods and methodology.

In this opening chapter I present a reflexive account of my own personal journey into the world of research. The chapter offers the reader the opportunity to explore the positioning of this thesis. It details the source of my motivations in relation to the perspectives that are researched, analysed and discussed in the ensuing chapters. At the risk of becoming an “emotional exhibitionist” (Ellis and Flaherty 1992) this chapter acknowledges me, ‘the person’, in the process of qualitative research. Callaway (1992 p. 33) describes reflexivity as,

*‘opening the way to more radical consciousness of self in facing the political dimensions of fieldwork and constructing knowledge ... reflexivity becomes a continuing mode of self analysis and political awareness’.*

The account is based on the life story work described by Gubrium (1993) in which he sharpens the traditionally qualitative research issues of normalising, consistency, and emotionality focusing on bio-graphical data.

I also provide this reflexive account as a context for the design that sits at the heart of this thesis; namely, the appreciative inquiry 4 ‘D’ cycle preliminary stage information gathering (Whitney and Trosten-Bloom 2003). As it was with the participants in the study, it became necessary for me to do this by reflecting upon some of the more stressful and sad times of my life. I was also mindful that, traditionally, appreciative inquiry is,

*'a period to collect and share the story of exceptional accomplishment'* (Cooperrider *et. al.* 2005 p. 39)

## **My Personal Journey**

### ***Early years***

I grew up in a community where family values and attitudes were the ethos of each child's development. I lived in a comfortable 3 bed roomed house with my parents and younger brother in a quiet 1950s modern semi-rural area of Kent. My childhood was one of outside activities and blissful days in fields and gardens of a leafy suburbia. Primary school was a bus ride away and my years there passed in a flurry of sporting activities and friendship groups. The issue of academic level did not raise its head until the day of the 11 plus. This was the first real change that I remember in my life. I failed the 11 plus and after much soul searching on my parents behalf, about which school I should attend, I found myself at a large secondary modern school with all the negative connotations that surrounded it. Bullying, racial remarks, derogatory comments and 'being put down' were part of daily life. This experience has remained with me to the present day. However, I was one of the lucky ones, I had supportive family, good friendship skills and was seen to be one of the 'bright ones'. I eventually left secondary school as a 'success' with 7 'O' levels and a typing and shorthand qualification to enter the work place as a secretary, a worthwhile occupation but not one I wanted to commence at this formative time in my life. Indeed, this limited expectation may be one of the reasons why I took my next steps into the nursing field, although I had apparently spent most of my early childhood 'bandaging' pets and friends in the garden shed.

My teenage years hold memories of strong friendship groups, parties, music and a Saturday job in a curtain fabric shop. Those friendships have held together over the years and I still see

many of the people I met at that time. I moved to London when I was 18 years old and continued enjoying the social life of the capital city whilst starting my career as a nurse.

### **Nursing Career**

I started my nursing career as an 18 year old school leaver in the mid 1970s. My introduction to nursing was exciting and the first 6 weeks of ‘Preliminary Training School’ passed in a whirl of new relationships, learning and independent living in a big city. The course I had chosen was a pilot course involving 4 years of training to include state registration (RGN) and registered mental health training (RMN). We were a small set of students amongst significant numbers of ‘general’ nursing students and throughout our student years were viewed as ‘slightly odd’ and ‘different’ to everyone else. We were always the ‘general’ students in a mental health placement and the ‘mental’ students in general placements. Those first few weeks of training were based on the very strict ‘Nightingale’ rules where no visitors were allowed in the nurses’ home, everyone was in their room by 10.00pm with a glass of milk given out by an unnecessarily strict matron. The uniform code was equally strict with each dress being handmade and then soaked in copious amounts of starch that made for sore necks and stiff arms. Each button was safety pinned to the dress and apron and the numbers of buttons and safety pins strictly accounted for by the ward sisters. I had nightmares for many years about safety pins and buttons.

My initiation to the wards, a medical ward, was not too stretching for me as it closely matched my expectations of a task orientated pattern of care with a number of skills to be learned and ‘signed off’ in my assessment book. I then completed an acute placement in mental health, comfortable with the new and innovative approaches to care that I experienced. Group therapy work was common place and a new ‘mother and baby’ unit was being introduced. By the time

I was placed onto one of the top floor ‘psycho-geriatric’ wards, I had somehow fallen into the misconception that mental health care was changing, the large institutions were closing and institutionalisation was not coming my way at this innovative teaching hospital.

In preparation for the placement on the psycho-geriatric ward, I had been told to wear uniform and to be prepared for it to be ‘heavy’. I arrived at the locked door for an early shift; I was quickly shown to the twenty eight bedded ‘Nightingale’ style dormitories. Each elderly lady was in a state of either undress or lying in bed, the smell and noise was overwhelming. Two Auxiliary Nurses were systematically ‘commodeing’, washing and dressing the ladies and informed me to “start the other end and work my way up”; everything I needed was on the locker. Beside the first bed was a frail elderly lady slouched on a commode without a stitch on ..... my shift continued. At the end of the day I went to see my tutor. I was horrified at what I had seen; he told me I had two choices: either complete the placement or leave my nursing career that afternoon. He also said that the only way to change things was to ‘work at it’.

I did return and finished my placement. I also took note of the conversation with my tutor and with his support looked at mealtimes and the practice of ‘commodeing patients’ at the dining table. This practice was changed towards the end of my placement. However, the experience and exposure to practice on the psycho-geriatric ward had a profound effect on me. The meaning of ‘caring’ rather than using task driven processes had been raised for me.

### ***Relationships***

I married in 1977 aged 20 years and moved back to Kent the year after. Together, my husband and I renovated 2 houses before having our first daughter and 2 years later planned our next child. The next event in my life illustrates this and connects with some of the carers’

reflections later in this thesis. At the end of 1984 my life changed forever, my husband died suddenly leaving for work in the morning and never returning. An undiagnosed congenital heart condition shortened his life to 27 years. We had been married for 7 years and had known each other since we were 16 years old. It was then, finding myself alone with a 3 year old and pregnant with our second child, that I realised the importance of family, friends and colleagues. They literally carried me through the next year. All the relationships and life experience skills I had learned and connected with became the centre of my life.

I gradually stabilised my life. My second daughter arrived safe and well, I returned to work and life started to begin again. New relationships developed from old ones and I re-married in 1986 to a friend I had known from my school days. We moved house and areas and the first day he was called ‘daddy’ we knew we were on the right track. My third daughter was born in January of 1988, a tiny premature baby dependant on the special baby care unit. Our trust and hopes were placed with that professional team for several weeks before we could take her home. The importance of being able to communicate with the team of professionals and know our baby was safe and being well cared for was central to our life for that short period of time. We still remember them 21 years on.

Other events have crafted my life bringing varied amounts of joy and sadness all intertwined with self development. I find myself feeling privileged that my life so far has been so preciously supported by the people around me; family, friends, colleagues and acquaintances.

### ***Dementia Care Nursing***

In my nurse training I was lucky enough to be working in the same hospital as Dr Brice Pitt (Pitt 1987). Although not aware of how innovative his work was at the time, I was one of the

fortunate students who benefited from working in the new community focused psycho-geriatric service. Changes and approaches to psycho-geriatric care were happening quickly and my next psycho-geriatric placement was very different. Patients had their own clothes for one thing and essential individual care and support for the family was slowly being implemented. I felt the theory was beginning to catch up with the practice. In my first psychiatric book the text reads,

*'It is desirable for him (the patient) to have as few changes in nursing attendants as practicable. If the presence of one member of his immediate family reassures and relaxes him this should be encouraged – but the doctor should be asked to forbid visiting if this is obviously distressing him. Quietness and gentleness in the nurse's movements are essential; soft, repeated reassurances may be found in some instances to be the best 'tranquilliser' available'. (Maddison et. al. 1971 p. 426)*

Again I slipped into a comfort zone of believing that care for people with dementia was changing, and although the accepted terminology of the time now appears strange and demeaning, those people with 'senile dementia' appeared to be receiving a service that met their needs. Of course, my limited experience was in one small geographical area of East End London and I learnt over the years that again I couldn't have been more wrong. I qualified in 1979 as an RGN and RMN giving me a wide choice of staff nurse posts. Towards the end of my training I had developed an interest in women's health and took a post on a surgical gynaecology ward. This was a challenging area that stretched both my limited mental health experience and my general experience. The psychological support to women in the late 1970s around life changing surgery was very limited and I immersed myself in helping to encourage nurses to talk to patients about forthcoming major surgery and the potential life changing results it would have.

After a year we moved house from London to Kent where I worked as a junior staff nurse in an acute admission mental health ward of a local general hospital. The highly technical and modern approach to mental health was barely evident on this ward. Reflecting back today I can see that the fact it was not based in a large psychiatric hospital but was a first step to moving acute mental health into the community. A community team was set up whilst I was in post and I was keen to be part of it. I was rejected at interview for being too young and pretty and would pose a risk when working alone in the community. I cannot imagine being rejected for these reasons today but accepted it at the time. My growing interest in community work then led me to apply for a district nurse post for which I was accepted. In this post I had found my comfort zone. I was delighted with the autonomy I was allowed and the variety of clinical work I could accept onto my case load. I completed my district nurse qualification in 1981 and worked in the South London area until 1986.

My work life then became secondary to my personal life for 6 years for reasons I have outlined earlier. I returned to my career six years later and worked as an agency nurse in many different areas; acute mental health, occupational health and the care home sector. A chance meeting with another ‘mum’ at the school gates introduced me to working with carers. This was a 3 year project that I shared part time with a physiotherapist, to investigate the needs of family carers who were caring for a person following a stroke and the training needs of care workers in the care home sector. Over the 3 years we developed and had validated a National Vocational Qualification level 2 programme for care workers in the care and community services in Maidstone Kent. This work generated income to support the work with family carers of people following a stroke. In the mid 1990s this type of work was seen as innovative and we were able to evidence the support of physical and mental health needs of the carer. At

the end of the 3 years the project was fully funded as a permanent service, I remained in the service for a further two years.

My interest in working with carers was already well developed when I accepted the post of Admiral Nurse. I have worked as an Admiral Nurse for 9 years. The first 3 years I was clinically based working across a wide rural area of Kent. In 2003 I accepted a post as a Lecturer-Practitioner at Canterbury Christ Church University. The University had an underdeveloped dementia curriculum when I took up my post giving me the opportunity to develop a more robust and enhanced Higher Education dementia programme. My teaching responsibilities now involves dementia care in the Inter-professional Professional Registration programme, 3 modules at level 3 in the Continuing Professional Development Programme and 2 modules in the level 4 Masters Programme. Both degrees offer a dementia care endorsement.

### *Embarking on the research journey*

Embarking on academic research study has been the next step for me; circumstances fell into place in what seems like a natural order to allow me to take up this journey. My 3 daughters are grown up and lead independent lives and my husband's business is developed and steady. The most important factor about embarking on this research journey for me was that the research should make a positive contribution to the lives of carers, people with dementia and support the future practice and development of Admiral Nurses.

Throughout the 30 years I have been a nurse I have observed the gap between practice and the evidence base that informs the practice in dementia care. Thankfully, practice has changed in many ways and my career has taken various directions over the years. When I accepted the

post of Admiral Nurse my years of experience as a general and mental health nurse were for the first time consolidated. Admiral Nursing has given me the opportunity to be able to address the needs of the carer and the person with dementia and quite often the wider ‘family’.

## **Summary**

The personal experiences I have described in this chapter are an illustration of some of the relational and emotional turning points of my life. They provide an insight into how my life has shaped my values and beliefs. My life and nursing career feel closely entwined with my personal experiences impacting on my nursing practice and philosophy of nursing. This chapter is a reflection of some of my own life experiences highlighting that as a researcher I hold empathy for the feelings of loss and grief and the feelings of well-being and achievement. I have continued to focus my clinical practice and academic work around achievement and appreciation of ‘what is the best of’ and ‘what can be achieved. I hope this focus will now be reflected in the approach to this thesis.

## **Chapter 2**

### **Dementia: a contextual description**

In Chapter 1 I described some periods of my life that have great meaning to how I have continued building and developing my personal relationships and career pathway. The impetus for this study has emerged from those life events and my experience of working with people with dementia and their family members (Segaric and Hall 2005). This background framed the nature of the study and was integral to it. Chapter 2 outlines my research journey and places my thoughts and ideas within the context of dementia and starts to define the temporal nature of the study. The chapter begins with a perspective on UK policy (up until 2007) on dementia taking the publication of the National Institute of Clinical Excellence and the Social Care Institute for Excellence (SCIE) guidelines '*Dementia: Supporting people with dementia and their carers in health and social care*' (clinical practice guideline 42: NICE/SCIE 2006) as its anchor, particularly the report's promotion of a bio-psychosocial model of dementia. The chapter also considers the demography and prevalence of dementia and describes its biological perspective with reference to clinical features. A psychosocial perspective of dementia is also addressed which includes a review of person-centred and relationship-centred care. The chapter concludes with a contextual description about the caring role in dementia.

### **The Policy Context**

Over the years, and from a UK perspective, there has been a growing recognition of the need for specialist services to older people and a distinction between patients' and carers' needs. Arguably, a starting point was the publication of the NHS Community Care Act (DH 1990) which separated health and social care needs and transferred responsibility for meeting the

social care needs of older people to local authorities. At this time, providing focused care to family carers was relatively new to health and social care practitioners. As a pre-cursor to policy development, Twigg and Atkin (1994) and Nolan, Grant and Keady (1996) were amongst the early researchers considering carers' needs, raising awareness of the importance of supporting a carer's health and social care needs to support the cared for. In 1995 the Carers (Recognition and Service) Act changed the way that health and social care recognised their work and assessment of family carers (DH 1995). At this time it became statutory responsibility to offer a carer an assessment in their own right when the person they were caring for required an assessment. Although this was a significant step forward for carers of people with dementia, it did little to support them with practical help and services as people with dementia were often not identified to have a social or health care need until a point of crisis was reached (Janlov *et. al.* 2006).

Policy has continued to promote carer related services across the spectrum of health and social care (see for example: DH 1999b; DH 2000; DH 2004). The voices of carers of people with dementia remain largely inaudible although there have been other national policy drivers to help hear their voices (DH 2001; DH 2006). However, policy has given enormous emphasis on developing dementia services and addressing the needs of people with dementia and their carers.

At the end of the 1990s the National Service Framework (NSF) for Mental Health was published (DH 1999a) which explicitly overlooked adults over the age of 65. Two years later the NSF for Older People was published (DH 2001) setting out eight standards with a ten year programme for action and reform to deliver quality standards to older people. Standard seven

specifically addressed the care of older people with mental health needs emphasising the need to treat and support older people with dementia and with depression. Three key interventions were advised, promoting good mental health (1), early recognition and management of health problems (2) and access to specialist care (3). To support the three interventions advice on establishing good practice was given for the treatment of people with dementia (DH 2001 p. 90):

- explaining the diagnosis to the older person and any carers and where possible giving relevant information about sources of help and support.
- giving information about the likely prognosis and options for packages of care.
- making appropriate referrals to help with fears and worries, distress, practical and financial issues that affect the person and their carer.
- using non-pharmacological management strategies such as mental exercise, physical therapy, dietary treatment alongside drug therapy.
- prescribing anti-psychotic drugs for more serious problems such as delusions, and hallucinations, serious distress or danger from behaviour disturbance.

Disappointingly, there was no funding attached to the NSF for Older People (DH 2001) although, on a positive note, the framework challenged organisations to refigure services using creative ways to meet the targets.

Further attention was not given to this until the follow up report to the Forget-Me-Not Report (Audit Commission 2000). The Forget-Me-Not report (Audit Commission 2000) highlighted the lack of understanding about dementia in primary care. General Practitioners reported a

sense of helplessness in actively making an early diagnosis as there was little that could be done for the person with dementia. A follow up report *Forget-Me-Not* 2002 (Audit Commission 2002) reported that there had been little change in the two years from the publication of the first report.

Further developing the policy and practice context, in 2005 the DH published *Securing Better Mental Services for Older Adults* (DH 2005a). This was a landmark publication promoting a joint vision for improving services for people with dementia. The vision included:

- services to be based on needs not age
- all services to view people as a whole taking into account their physical and mental health needs
- organisations working together to provide best quality care
- training staff who work with people with dementia so that they can recognise when to refer to a specialist service
- investment into older people's mental health service provision.

In the same year, and in recognition of the challenges of implementing their vision, a service development guide *Everybody's Business: integrating mental health services for older adults* (DH 2005b) was published. The vision inherent in this publication was to inform local discussions for the commissioning agenda, to outline provision of services and to provide 'best practice' guidance (DH 2005b). The guide (DH 2005b) identifies the needs of people with dementia in primary and community care, intermediate care, care for people in general hospitals, specialist mental health services and special groups.

Efforts to integrate care and mental health expertise for people with dementia were taken further in 2006 with the publication of NICE/SCIE guideline 42 '*Dementia: supporting people with dementia and their carers in health and social care*' (NICE/SCIE 2006). The publication once again emphasised the importance of collaborative working and that the needs of people with dementia do not easily fit into one category. The guidelines aim to:

- improve older people's quality of life
- meet complex needs in a co-ordinated way
- provide a person-centred approach
- promote age equality.

This ground-breaking publication reviewed the evidence on current dementia care practice providing guidance on how to establish joined up services for people with dementia and their carers (NICE/SCIE 2006). By taking a care pathway approach, the guidance considers the impact of dementia on the person, their family and wider a social circle from when they first identified the onset of the condition. This is achieved by a targeted neuropsychological assessment and diagnostic process that considers good practice in all aspects of dementia care, including future and advanced care planning which may well involve end of life. This holistic approach is inclusive of younger people with dementia and those with a learning disability and dementia. The NICE/SCIE guideline 42 (NICE/SCIE 2006) promotes dementia as a bio-psychosocial model with a balance necessary between the bio-psychosocial factors in order for the person living with the condition, and their carers/family, to receive optimum care.

## **Demographic perspective**

Until relatively recently dementia was commonly referred to as ‘senility’ and accepted as part of getting old (Madison *et. al.* 1971). Today, this is no longer considered to be the case with dementia understood as a set of symptoms caused by damage to the brain (Knapp *et.al.* 2007). Dementia can affect a person of any age, but is most common in older people. Age and female gender are associated with a higher prevalence, with one person in 1000 aged 40-65 years; one in 20 aged over 65; and one person in 5 over 80 having a form of dementia (Knapp *et. al.* 2007). The report estimates that there are now 683,597 people with dementia in the UK. This is representative of one person in every 88 of the entire UK population. As people now live to a greater age this number is expected to increase in the future. For example, the total number of people with dementia in the UK is forecast to rise to 940,110 by 2021 and 1,735,087 by 2051, an increase of 38% over the next 15 years and 154% over the next 45 years (Knapp *et.al.* 2007). These figures do not include people with learning disabilities or people with dementia in NHS continuing care facilities.

The expected prevalence of dementia worldwide is expected to grow in conjunction with the UK figures. Demographic ageing is advancing rapidly in China, India and Latin America where the number of older people will have increased by 200% as opposed to 68% in developing countries in the 10 years up to 2020 (The Harvard School of Public Health 1996). Further prevalence studies published in 2005 found a trend towards a lower prevalence rate in developing countries as opposed to developed countries (Ferri *et. al.* 2005). Reasons for this are believed to be a younger mortality rate and cultural disregard to the milder symptoms of

dementia in the early stages. However, most people with dementia live in developing countries; 60% in 2001 rising to 71% in 2040 (Ferri *et. al.* 2005).

## The biomedical perspectives

The term dementia covers a number of symptoms accompanying certain diseases or disorders, resulting in deterioration of intellectual functioning, i.e. in memory, perception and routine.

There are many different causes of dementia and they vary in progression. A persistent perspective on dementia is the biomedical one highlighting its physiological and cognitive features. For instance, the World Health Organisation (WHO) defines dementia the following way:

*'Dementia is a syndrome caused by a range of illnesses. Most are currently incurable, and cause progressive, irreversible brain damage. They include Alzheimer's disease (the most common cause), vascular disease, frontal lobe dementia and Lewy Body disease. Symptoms of dementia can include memory loss, difficulties with language, judgement, and insight, failure to recognise people, disorientation, mood changes, hallucinations, delusions, and the gradual loss of ability to perform all tasks of daily living'.*

(WHO 2007 p. 1)

This definition categorises dementia as a syndrome that is not one particular type of condition but a variety of conditions with similar or common features. The word 'dementia' alone cannot describe the whole story; a more precise diagnosis is required to inform practice and instigate timely and appropriate care. Some of the most common forms of dementia are described below:

*Alzheimer's disease* is the most common dementia (Ferri *et. al.* 2005). The presence of amyloid plaques and neurofibrillary tangles in the brain were first identified by Alois Alzheimer in 1907 (Alzheimer 1907). Amyloid plaques are toxic to cells with the hypothesis

being that the disease process results from an imbalance between the production and clearance of amyloid precursor protein. This changes the chemical structures of the brain causing irreparable damage to the brain cells (Bayer *et. al.* 2001). The brain becomes atrophied with extensive loss of the grey matter (Bayer *et.al.* 2001). A definite diagnosis can only be given after identifying two core lesions of the disease at post mortem (Hyman and Trojanowski 1997). The course of the disease is one of slow decline to cognitive functioning and loss of daily living skills (Hardy and Selkoe 2002). As the disease progresses, the need for support and care increases and can last for up to 15-20 years (Cantley 2001 p. 12).

*Vascular dementia* is caused by the occlusion of oxygen to parts of the brain damaged by small strokes (trans-ischemic attacks), or small vessel disease (Bowler and Hanchinski 2000). Conditions such as, or associated with, hypertension, heart disease, diabetes or circulatory problems that affect the brain can cause vascular dementia (Chui *et. al.* 2000). Vascular dementia often has a sudden or dramatic onset and can be focal, for example loss of visual awareness and language skills (Chui *et. al.* 2000). A history of a step wise progression in cognitive impairment, being emotionally labile and lacking in motivation can aid a diagnosis (Alagikrishan 2007). This can be associated with evidence of stroke when the prevalence of dementia is ten times higher than the general population, (Alagikrishan 2007).

*Frontotemporal dementia* is an umbrella term for a number of uncommon diseases, including Pick's Disease. It is more commonly associated with people under 65; most people show symptoms after the age of 40 (Yeaworth and Burke 2000). In the early stages, symptoms include changes in behaviour and personality, differing from Vascular dementia and

Alzheimer's disease in that in the early stages the memory often remains intact (Graff-Radford *et. al.* 1990). The definite diagnosis of Pick's Disease rests on finding 'Pick's Bodies' in the affected cells and swollen or ballooned cells in the cortex of the brain at post mortem (Neary and Snowden 1996). Brain imaging usually identifies 'Pick's Bodies' confined to the frontal lobe and anterior temporal lobes classifying it as fronto-temporal dementia (Graff-Radford *et.al.* 1990). The average duration of the disease is 5 years but has been known to have a longer duration in some patients (Boxer and Miller 2005). The process of diagnosis for this type of dementia is often long and complicated therefore impacting on the family at a very early stage (Yeaworth and Burke 2000).

*Dementia with Lewy Bodies* is caused by small spherical protein deposits that develop within the nerve cells of the brain. These interrupt the brain's normal functioning, affecting memory, concentration, language skills and motor response. The main features of dementia with Lewy Bodies are fluctuating cognition, visual hallucinations with Parkinsonism, extreme sensitivity to antipsychotic agents and rapid eye movement sleep disorder (Neef *et. al.* 2006). Some conditions such as depression, brain tumours, nutritional deficiencies or drug reactions, may mimic a dementia and can be successfully treated to restore cognitive functioning.

Treatment options for Alzheimer's disease are medication based on the 'cholinergic hypotheses' which maintains that as a result of underlying pathological processes, neurons that use acetylcholine, critical to memory and learning are positively affected (McKeith *et. al.* 2005; Galvin 2003). Recent advances have seen the production and prescribed use of acetylcholinesterase inhibitors (Kaufer 2004). These drugs increase the amount of

neurotransmitter available by inhibiting the action of the enzyme responsible for its deterioration. NICE/SCIE provide practice guidance related to the use of this medication (NICE/SCIE 2006). For the other dementias described treatment options using medication require a careful balance to manage symptoms of the dementia and the side effects of the prescribed medication (NICE/SCIE 2006).

Use of the bio-medical model without recognition of other approaches to understanding the construction and meaning of dementia means that neither the person with dementia nor those in supportive roles are seen as being active contributors to care. The person with dementia is viewed as not having a sense of self or identity (Kontos 2005). In the next section this point will be balanced by describing the psychological perspective of dementia care.

## **The psychological perspective of dementia care**

The pioneering work of Tom Kitwood (see Kitwood 1997) has exerted a major influence on the field of dementia care. The application of ‘person-centred care’ has become the essence of ‘best practice’ in the dementia field and has influenced UK policy formation and construction (DH 2001). Examining the psychosocial approach to dementia reminds us that a person with dementia is no less a person than anyone else and efforts should be made to maintain and improve quality of life by respecting and preserving the individual’s personhood. To develop this further means that we take the perspective of how the person with dementia views their life rather than our perspective of how they should lead their life. As Kitwood argued the ‘dementia’ is not the problem; the problem is ‘our’ (individual, carer, professional, society) inability to accommodate ‘their’ view of the world. Therefore there is a danger of

creating/maintaining a ‘them’ and ‘us’ dialectic tension that has become reinforced over the years by the socially constructed and devalued status of someone who is ‘dementing’.

At the heart of Kitwood’s (1997) conception of person-centred care was ‘personhood’:

*‘Personhood: it is a standing or status that is bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect and trust.’*

( Kitwood 1997 p. 8)

Personhood is a recognition of the value of all human beings (regardless of race, sex, disability, age or cognitive ability) and is a status that one individual bestows upon another. In upholding personhood many societal factors are involved, such as culture, availability of support and services and, unfortunately, the negative attitudes that many professionals hold towards dementia may also diminish personhood. In the early days of his work with people with dementia, Kitwood (1988; 1989; 1990; 1993) became aware of ‘depersonalising’ tendencies. He observed within the care home sector how the well intentioned ‘other’ often misinterpreted the communication attempts of the person with dementia, often labelling them as ‘challenging’ or ‘aggressive’. In this context Kitwood (1997 pp. 46-47) describes the behaviour of the ‘significant other’ as malignant social psychology. Malignant social psychology is perhaps the most negative aspect of care traditions and includes the types of task-orientated care I referred to in my reflexive account in Chapter 1. With a higher profile given to dementia education and training for professionals (Pulsford *et. al.* 2007), policy and quality advancements (NICE/SCIE 2006) and the rising voice of people with dementia to be included in educational programmes research and service development (Wilkinson 2002)

Kitwood's (1997) description of a malignant social psychology for people with dementia can begin to be challenged.

Person-centred care, according to Kitwood (1997), flowed from the conception of personhood. By reducing the excess disability that comes from poor quality care and the environment in which it is provided, the values of person-centred care has a direct impact upon care delivery. Person-centred care is a value system towards others derived by Rogers (1961) and introduced to dementia care by Kitwood and Benson (1995); the approach reflecting a way of being that shows respect for each person's unique individuality. Person-centred care acknowledges that each person with dementia has the same human value, shares the same human rights and has the same varied human needs as every other person. Person-centred care is a philosophy of care that places value on empowerment, enablement and independence. Kitwood (1997) espouses the principles of person-centred care which enable the person with dementia to exercise choice, use their abilities, express their feelings and maintain relationships. Kitwood (1997) argues that if such positive conditions, attributes and environments are present, then 'rementia' can take place, a phase that often manifests itself in subtle changes to cognition and functional abilities (Sixsmith *et. al.* 1993). Kitwood's (1988) equation suggests each person's unique physical and emotional identity and a related life experience provides a framework for recognition of dementia symptoms SD = P + B + H + NI + SP:

SD (senile dementia) =

P = Personality, which includes coping styles and defences against anxiety;

B = Biography, and responses to the vicissitudes of later life;

H = Health status, including the acuity of the senses;

NI = Neurological impairment, separated into its location, type and intensity;

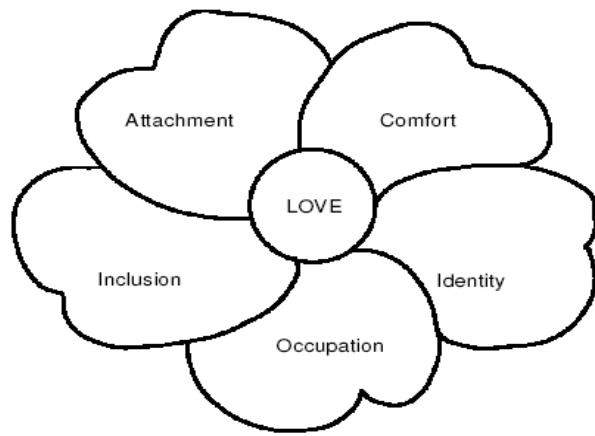
SP = Social psychology which constitutes the fabric of everyday life.

Kitwood and Bredin (1992) describe the offsetting of the fragmentation of selfhood by using the term ‘person work’ as the ultimate goal. This is an approach that is becoming central in dementia care practice where person-centred approaches are derived from psychotherapy and psychiatric approaches, e.g. validation, reminiscence, groups, life story work. The psychological origins of person-centred care are linked to the central premise that a state of wellbeing (equated to the maintenance of personhood regardless of cognitive state) is dependent upon fulfilling various psychological needs (Kitwood 1997 pp. 81-84). The disabilities that occur with a dementia often mean that these needs are more difficult to achieve making the goal of Kitwood’s notion of person-centred care an attempt to compensate for the deficits associated with the symptoms of a dementia (Kontos 2005). Reflecting on current practices the greatest obstacles to person-centred care lie in the fear and distress of seeing and managing a person deteriorate from ‘the person they were’ and ‘traditional’ task orientated practice.

### **Relationship-centred care**

Figure 1 illustrates that central to the identified psychological need of the person with dementia is love, closely attached to the other five vital elements of psychological wellbeing (Kitwood 1997).

**Figure 1 The main psychological needs of people with dementia (Kitwood 1997 p. 82)**



To be able to love, receive comfort, be included, have attachments to others, be occupied, and have an identity implies the person with dementia has to be engaged in relationships with others (Skynner 1976).

Kitwood's untimely death did not give him time to develop his theory further, but exploring the concerns of the validity of the approaches to person-centred care has given rise to exploration into alternative ways to care that remain rooted in core values (Nolan *et. al.* 2004). In this context Keady and Nolan (2003) explore how couples, who were in the early stages of coming to terms with a diagnosis of dementia, coped with its challenges. These authors interviewed family members and people with dementia identifying four kinds of relationships, three of the relationships being reliant on both partners working as single units and one where partners worked together. Hellstrom *et. al.* (2005) describe a similar relationship-centred approach in Sweden where in a detailed case study, an older couple marry and shortly afterwards find that one of them has dementia (wife). Her husband tells how they were surprised by the diagnosis but manage it in a way that is sensitive, bringing meaning to their relationship by communicating a reinforced positive view to their future relationship.

Through framing care processes through a relational lens, Nolan *et. al.* (2004) offer a way, of capturing the salient dimensions of inter-relationships and, as applied to my reported study, the relationship between the person with dementia and the professional. The Senses Framework was developed to capture the important aspects of caring relationships and reflects the dynamic process of giving and receiving care (Nolan *et. al.* 2006). The Senses Framework is constructed around the ethos that those living with the condition, their family members and statutory care providers should experience the kind of relationship that can offer security; belonging; continuity; purpose; achievement and significance (Nolan *et. al.* 2006).

### **The carer context**

The report '*Our Health, Our Care, Our Say for our Caring Future*' (DH 2007) published in February 2007 received 3,000 respondents to a survey of carers' priorities. One in five carers identified greater recognition by professionals as their highest priority. Carers do not always have the choice about caring, but most people given the choice, would continue to care. Carer's support has been valued at a staggering £57 billion per year. By 2037, the number of carers will have to rise to 9 million to keep pace with the rising levels of frail and disabled people. The key priorities for change that Carers UK believe should be addressed in the review of the National Strategy for Carers (DH 1999b) are:

- better recognition of the role of carers from professionals,
- income from benefits for the under 65s,
- carers health, and,
- better services for those whom they care.

Historically, research with carers of people with dementia has focused on, relationships, health of the carers and the relief of stress and burden (Zarit and Zarit 1982; Zarit *et.al.* 1985; Zarit *et.al.* 1987; Pearlin *et. al.* 1990; Nolan *et. al.* 1996 and Sheard 2004a,b). Although there is evidence that not all carers of people with dementia find their role burdensome and with the appropriate support, information and education it can be a positive and fulfilling experience (Schumacher *et. al.* 1998; Lombardo 2003; Andren and Elmstahl 2005). Dementia affects everyone in the family from before a diagnosis has been made to the years after the person with dementia has died (Steeman *et.al.* 2006). Services for family carers are often led by voluntary groups or seated with social services whilst services for the person with dementia are seated in primary care or secondary mental health. Difficulties of repeated assessment, confidentiality and sharing of information across organisations can cause a fragmented pathway of care for the family and person with dementia throughout the trajectory of their journey through dementia. For some families this causes unnecessary relational tensions, feelings of isolation, reluctance to engage with services due to fear of separation, increased feelings of guilt, stress and burden (Keady and Nolan 2003). Specific research into care of people with dementia shows a need for attention to relationships, health of the carers and the relief of stress and burden (Clarke 1999; Keady *et. al.* 2007a; Sheard 2004a, b; Nolan *et. al.* 1996).

Providing focused care to family carers is relatively new to health and social care practitioners. From my own experience of practice care is more usually provided to the sufferer with the focus on the carer being secondary. As previously mentioned Twigg and Atkin were one of the first to research carers' needs in the 1980s and 1990s raising awareness of the need to support a carer's health and social care needs to support the cared for. Traditionally, it has been the family who have provided long term care to the older person

living in the community and is often the assumption that the caring role will be fulfilled by the wife or eldest daughter (Twigg and Atkin 1994).

In the future, most people's lives will include at least one episode of caring. In the UK there are over 1.5 million people aged 60 or over providing unpaid care. Over 8,000 carers are aged 90+, 4,000 of these very aged carers provide 50 or more hours care each week (Yeandle and Buckner 2005). With the estimated numbers of people with dementia rising, these numbers will include a significant number of carers caring for a person or persons with dementia. This, in turn, will have the potential to make significant impact on the way that families are involved in the care of people with dementia. In Chapter 3 I focus the attention of this thesis on family-centred approaches that have a synergy with the context of this study providing a platform for the study design and data collection.

## **Social Construction of Caring for a Person with Dementia**

*'... if I ask about the world, you can offer to tell me how it is under one or more frames of reference; but if I insist that you tell me how it is apart from all frames, what can you say?'*

(Nelson Goodman cited in Gergen 2007 p. 33)

Berger and Luckmann (1967) argue that knowledge is unevenly distributed in society and that access to specialist medical knowledge has become particularly uneven. When relating this to carer knowledge it is also prudent to consider their argument that medical practitioners have 'recipe' knowledge to meet competences in routine performance. They do not necessarily have the full knowledge required to provide a specialist intervention. On the other hand, it can be argued that a carer caring for a person with dementia has extensive knowledge about the

person with dementia (Keady and Nolan 2003). The need to have knowledge about medical pathology, historical theories and narratives have been developed to provide a negative connotation of carer value and wellbeing which, in turn, has loaded the caring role with the stigma of burden.

From an observational point of view all social action is open to multiple interpretations, none of which are superior to another in any objectified sense. The most powerful vehicle communities have for making change in the social order is through the act of dialogue made possible by language (Palfrey and Harding 1997). Alterations in linguistics therefore hold profound implications for change in social practice; in other words, people are defined by the power of language. To take one simple example of this phenomenon, the use of the saying '*give a dog a bad name*' can be detrimental to those on its receiving end by stigmatising people into categories or '*ghettos*'.

When examining the culture of care to carers in dementia three themes can be identified within the boundaries of health and social care, the traditional approach (1), this is the answer; the modern approach (2), let us experiment and compare with the real world; and (3), the person centred approach (Kitwood 1997). So, when considering caring for a person with dementia whose actions are right, whose are wrong and who is in the position to judge? Finding a way to facilitate this dialogue is one of the aims of this thesis, shifting power from the professional to the carer and carers having a legitimate voice to drive a positive reality. Valid knowledge or social theory is a narrative creation. Social 'knowledge' is not out there in nature to be discovered through detached, value-free observational methods (logical empiricism); nor can it be relegated to the subjective minds of isolated individuals

(cognitivism) (Palfrey and Harding 1997). Social knowledge from this perspective resides in the stories of the collective it is created, maintained, and put to use in a human group.

Dialogue free from constraint of distortion is necessary to determine the ‘nature of things’ (social constructionism).

Placing such observations within dementia care, Parker (2007) applied Bourdieu’s (1977) framework and reflected on how the biomedical model of disease, its pathology and the developing psychosocial approach to dementia, may act as an objective social category that structures the meaning of dementia for individuals practising in health and social care. An understanding of both active and cognitive practice is then reflected back to reproduce the objective category of dementia found in the biomedical and psychosocial model. If adopted uncritically it is possible to exclude the individual and their subjective experience which may disadvantage those with dementia and give low priority and/or status for those working in the field (Parker 2007).

It is important to acknowledge the importance of the academic’s involvement in the reconstruction of concepts and practices. Smith’s (1987) feminist sociological view is that the ongoing and co-ordering of activities brings the world into being, adding that the researcher is also part of that world in which the practices take part and that knowledge produced, gained, or created becomes part of that world. The communication between researcher and participant is in part constitutive to dementia. The act of interviewing, choice of environment, biography and predilections of the researcher influence the data gathered and the analysis and presentation of findings. Therefore, the researcher may be important to the constructs of dementia through the examination of practices in that given situation. When applied to

research of dementia practice, it is clear that asking the questions can potentially initiate change or change action and can positively reduce stigma.

## **The nursing context**

Nurses remain the largest professional body who are involved in the care of people with dementia (see Keady *et. al.* 2003 for more information). In the 1960's community psychiatric nursing with older people developed as a specialty in the UK alongside the generic CPN. The approach to care however was developed largely using the bio-medical model with little attention given to the support of the carer (Adams 2005). In the late 1990s as the process of diagnosis and assessment of dementia became more thorough, treatment options started to become available and national policy began to drive practice, the role of the CPN began to develop into a potential early intervention service. However, experienced CPN's noted that interventions were largely absent at time of crisis or extremes of carer stress (Clark 2003).

Adams (1996) highlighted the need for carers to receive information about the diagnosis of dementia, services and support networks. Indeed, Adams (1996) stated that CPN's found it difficult to terminate an intervention with a person with dementia if carer distress, illness or disability remained evident. This was compounded by the feelings of the CPN about the social nature of their relationship with the carer interfacing with the fear that 'something may go wrong' if they did not keep in contact with the patient and carer (Adams 1996).

The CPN model of nursing encompassing family needs was beginning to be constrained by the need to meet service provision targets and reconfigurations that national policy had been developed to support (DH 2001). At the same time as these developments further research

with carers of people with dementia was highlighting their specific need for professional and specialist support (Clarke *et. al.* 1993, Twigg 1993; 1994; 1995), a specialist focus which was taken up by the Admiral Nurse service.

## **Focus of the study**

Anecdotally the Admiral Nurse Service is well evaluated and carers of people with dementia are continuously asking for a service in their local area (Clare *et. al.* 2005). A number of articles demonstrating the efficacy of the work of the Admiral Nurse are available (see for example Soliman 2003; Keady *et. al.* 2007b; Thompson and Devenny 2007). Each carer's experience of being with a person with dementia is different and whilst there is considerable research that focuses on carers of people with dementia looking at stress and burden (Zarit *et. al.* 1982; 1985; 1987 and Pearlin *et. al.* 1990) few studies have explored carer wellbeing from a carers' perspective. This gap has overshadowed the satisfaction found within the caring role.

Indeed, Solomon (2003) suggest that:

*'There are serious limitations to assuming patients make decisions autonomously and out of context of the family, culture, community, and the particulars of a given situation. The patient and the family need to be 'the unit of care'.*

(Soliman 2003 p.171)

Before I began this inquiry there were no studies that had built up a picture of how a carer can work with an Admiral Nurse using a family-centred approach. This thesis explores carers' values by listening to their stories and examining visual images of their day to day lives. Through listening to carers, people with dementia, Admiral Nurses and stakeholders and interpreting the data the relationship between the Admiral Nurse and the carer is revealed. From this standpoint, knowledge is generated about what carers value about the family

approaches to care they receive (this may be from family members or professionals), and what Admiral Nurses hold as key principles and values underlying their practice.

## **Summary**

For many years the behavioural changes observed in people with dementia have been attributed solely to brain damage. More recently it has become evident that in addition to the brain injury people with dementia live with the psychological impact of managing changing symptoms caused by the brain injury, this in turn affects what they do and say when relating to others. The psychological and relationship approaches were reviewed and the importance of a bio-psycho-social approach to understanding the context and construction of dementia identified. The chapter also addressed the emerging body of work on the importance of relationships for the person with dementia as a development to Kitwood's (1997) person-centred approaches. There has however, been little developed on the importance of the carer maintaining their personhood and value of self and how, in these very complex situations, the wellbeing of the carer can be supported in context with the person with dementia and their wider family. In Chapter 3 I undertake a review of the family-centred literature identifying the key aspects of family-centred approaches in nursing.

# **Chapter 3**

## **A Family-centred approach a literature review**

### **Introduction**

In the Preface to this thesis I discussed the background to Admiral Nursing and how the research of Zarit and Zarit (1982); Zarit *et. al.* (1985); Zarit *et. al.* (1987) and Pearlin *et. al.* (1990) was adopted to provide the evidence base to Admiral Nurse practice. As Admiral Nursing has developed an anecdotal tension has emerged about the underlying value and philosophy of Admiral Nursing. There has also been a move in dementia care to highlight the importance of the relationship between the person with dementia and their carer/family (Kitwood 1997, Keady and Nolan 2003 and Nolan *et. al.* 2004). This has resulted in the possibility that Admiral Nurses, who focus primarily on the carer, may not be operating in an inclusive way.

In Chapter 1, I reflected on my career as a nurse, outlining the traditional attitudes and beliefs that all nurses have held. Examples including, being loyal and obedient, exercising mental restraint, and stating facts or self-formed opinions have been hard to change (Maddison *et. al.* 1971). Nurses have been constantly reminded that this was the ‘correct’ way to practice even as early as the 1970s when nurses remained very much in charge of their patient with a hierarchy of health care professionals ‘above’ them (Maddison *et. al.* 1971). Relatives were not encouraged to visit or be involved in the care of the patient until the 1960s and 1970s, when it was recognised that hospitalisation was not only expensive in the care of the chronically sick, but not always the best way of delivering care on an individual needs basis.

In chapter 2 I have given a brief over view of how relational care has begun to develop in dementia care. I also gave an over view of the models of dementia, biomedical psychological and relational approaches to dementia care. In the description of the nursing context of people with dementia I highlighted the work of Adams 1996, who discusses the ‘social relationship’ between the CPN and the carer. Anecdotally the Admiral Nurse now develops this relationship with the carer, person with dementia and larger family group as part of their day to day practice. As I started this research journey it was unclear what the meaning of the Admiral Nurse/carer relationship was.

The meaning of the relationship between the carer, the person with dementia and their family appears to be explicitly different to that of the interventions to support coping and behavioural strategies and support (psychosocial interventions) that have developed over the last 15 years. For example a practical intervention, arrangements for respite, the giving of educational materials, informative meetings and discussion groups. A study in the Netherlands based on the Adaptation-Coping Model found psycho-social interventions to be effective in the short term for carers and people with dementia (Droes *et. al.* 2004). The main drawback of this type of support was that it was invariably fragmented (delivered by a variety of services voluntary and professional), and had a short period of intervention for example, 6 – 10 weeks. The study highlights similar experiences of fragmented services for carers receiving psychosocial interventions in the UK (Knapp *et. al.* 2007; DH 2009). In particular relationships that were fostered with professionals within the time frame were gradually lost through the trajectory of the caring role (Finneman *et. al.* 2000; Droes *et. al.* 2004; Meiland *et. al.* 2005).

In 2003 Brodaty, Green and Koschera published a meta-analysis of psychosocial interventions for carers of people with dementia. Results of 30 studies (34 interventions) were studied from 1985 - 2001. Significant benefits were found in carer psychological distress, confidence, carer knowledge and person with dementia mood but not carer burden. It was noted that there was considerable variability in outcomes that may have been attributable to age, sex, type and severity of dementia and the prevalence of behavioural and psychological symptoms associated with dementia. The difference in methodology and intervention technique were also contributing factors, however, successful interventions (or elements of) were identified. Despite the limitations the studies held considerable importance to warrant further research for example, involvement of the extended family, structured individual counselling, and a flexible provision of a consistent professional to provide long term support (Brodaty, Green and Koschera 2003). During the time this thesis has undergone amendment these findings have now been underpinned by the UK policy document, Living well with dementia: A National Dementia Strategy (DH 2009) p.46.

Taking into consideration the development of Admiral Nursing it appears that a different approach to practice requires development to provide a meaning to carers that is more than providing coping and behavioural strategies and interventions. Anecdotal evidence from Admiral Nursing provides a basis to further explore family-centred approaches to practice and the meaning this has for carers

In order to have deeper understanding about the theoretical and methodological developments about how nurses work with carers and families, this chapter will provide a brief overview about how a family-centred approach has been developed and implemented in dementia care,

mental health nursing, and most predominantly, children's' nursing. The intention of including the literature pertaining to children is not to liken people with dementia to children. People with dementia are clearly adults with life experiences and individual nuances and personalities with an age range of approximately 40 – 90+ years. Families and people with dementia experience a social and relational death long before physical death (Small *et. al.* 2007). The rationale for including the children's literature is, that the similarities of the caring role hold a synergy with dementia care for example, the longevity of the caring role, the changing relationship between carer, the cared for and the wider family and the complexity of the illness/disability.

This overview of the family-centred literature also adds to the preliminary stage information to inform the appreciative inquiry 4 'D' cycle in Chapter 5. The review approaches the literature using a bibliographical review method to provide an overview of the literature base of family-centred approaches and to explore if Admiral Nursing has taken up concepts from other branches of nursing in order to develop a 'relational' approach to nursing with carers of people with dementia (Cook *et. al.* 1997).

## **Method of literature search**

A computerised search was conducted using numerous databases for studies published from January 1996 through to May 2006. All searches were limited to English language journals and studies focusing on family-centred approaches. Keyword searches of the interlinked search engines of the British Nursing Index and Ovid included the following databases: Journals@Ovid full text, Your Journals@Ovid, CINAHL-cumulative index to nursing and allied health literature, Ovid Medline®, PsycINFO. The following evidence-based medicine

databases were also searched for the period: [www.medscape.com/nurses](http://www.medscape.com/nurses), [www.bmjjournals.com](http://www.bmjjournals.com), Google Scholar <http://scholar.google.com>. Combinations of key words were used for these searches; family-centred dementia care, family-centred care, family- centred care carer, family-centred nursing, family-centred care paediatrics, family-centred care children, family-centred care mental health, empowerment, negotiation, partnerships, family-centred care nursing knowledge, family-centred care framework, expertise carer/family, competence carer/family.

In addition to the computerised search the library catalogue at Canterbury Christ Church University was searched using the same key words. References were examined in review articles/empirical articles and used to identify studies not captured through the database or catalogue searching. This was an important strategy for identifying studies including carer or family expertise and competence as family centred-care in mental health was not always explicit in the abstract of a journal article.

The literature was reviewed during the revisions of this thesis and includes references to 2008.

## **A Family-centred Approach**

Coyne (1996) in a review of the literature recognises that the origins of family approaches in nursing began in mental health nursing in the 1970s, which reflects the work of key leaders in the family therapy field for example (Minuchin 1974; Skynner 1976 and Epstein *et. al.* 1978). Mental Health Nursing at this time was developing an approach that encouraged the building of a relationship between the patient and nurse aiming to include patient and family in the ongoing care of the patient (Maddison *et. al.* 1971). In children's nursing however, the

development of family-centred approaches continued to develop. The main shift in children's nursing began after Bowlby published his work (Bowlby 1951) in the 1950s. This pre-empted changes in inpatient children's care, the most well known change being that parents were allowed to visit their children whilst they were inpatients (Hawthorne 1974). It was not until Bowlby's work was more widely disseminated, that psychological theories were examined and started to be introduced to nursing practice and the approach to care (Papalia and Wendkos-Olds 1995). From accepting the presence of parents on the children's wards, nursing studies began to demonstrate a shift in emphasis and a new stage of development of knowledge in children's nursing had begun. Nurse researchers moved from considering the impact of parent's presence to exploring attitudes and philosophy of children's nurses towards the family as a whole (Bradley 1996).

Family-centred approaches were further developed in the 1980s and 1990s as nursing theory was combined with concepts from family therapy experiences in nursing and psychology (Friedmann 1989; Whyte 1997). However, older people's mental health nursing did not go on to develop a family nursing approach in the same way as children's nursing developed. Mental health care went on to become somewhat fragmented in the way care was delivered in the UK, with the division of health and social care services and a focus of a pharmacological approach within the mental health community nursing services (DH 1990; Tennant 1993).

Whall (1981) explored how a paradigm for family nursing could be developed by making comparisons with the models of family nursing of Orem (1985) and Rogers (1970). Friedmann (1989) suggests that the family needs to be understood as the concepts of 'person' and of the 'environment' and this can be expanded further to explore a family-centred approach that, for the purpose of this review of the literature on family-centred value/psychological approach

will be reviewed. A family-centred value/psychological approach requires the skills of an advanced practitioner and goes beyond simple referrals or family members attending a group or medical clinic (Finneman *et. al.* 2000; Brodaty, Green and Koschera 2003; Droles *et. al.* 2004; Meiland *et. al.* 2005). Nethercott (1993) discusses this further, concluding that many nursing theories have been adapted to use with children, rather than being adapted to meet the needs of families and their children. With systems change in mind the nurse negotiates with the family a tailored change to meet the family's needs. For the change to take place the plan needs to be consistent with the general strategies that they use in daily coping (valuing, empowering, respect, partnerships, timing and goal directed, verified and evaluated) (Finneman *et. al.* 2000).

In the early 1970s, Laing (1976) was struggling with a similar dilemma in the field of psychiatry and schizophrenia and debated the fact that psychiatry was particularly concerned with individual experiences and behaviour that is regarded as 'abnormal' by our society *vis a vis* coming into line with views in medicine where attempts were being made to categorise experiences and behaviour into 'signs and symptoms'. Monahan (1993) discusses the need to provide a family-centred approach that enabled the professional to examine physiological, environmental and cultural factors as well as living arrangements. Following policy initiatives a shift in the paradigm of individual social, medical and psychosocial care into a family-centred approach framework had become and has continued to become increasingly evident (see comparisons in dementia care Chapter 2 p. 17 – 21). Monahan (1993) highlights the need for family-centred approaches in dementia care that work in partnership with and alongside the person and their family members rather than providing or supporting a clinically based treatment. As I reflected in Chapter 1, Monahan (1993) highlights that life events are not

independent, when one family member is faced with adversity so are others. Families have the capacity to effect changes in their relatives' lives that professionals can only guide.

Previous research supports this concluding that dementia makes huge demands on the family unit as managers and advocates (Zarit and Zarit 1982; Zarit *et.al.* 1985; Zarit *et.al.* 1987; Pearlin *et. al.* 1990; Sheard 2004a, b; and Nolan *et. al.* 1996). People with dementia and their families, like families caring for a chronically sick child, will be involved with a multitude of professionals during the course of their illness. This aids work with the person and family around issues like loss and grief but highlights that adult roles are not easily given up and the person with dementia often wants to remain independent to whatever cost (Chevannes 1997; Mitchell 2005).

It seems therefore without wishing to infantilise people with dementia, that a family-centred approach can provide a philosophical framework to reorganise systems of care, education and research. The Institute for Family Centred Care in America has developed guidance material to assist with the change from a systems orientated approach to family-centred care within its children's service, emphasising the importance of weaving the concepts and principles into the infrastructure of the organisation (Ahmann and Johnson 2001). An example of this is seen in Mackean *et. al.* (2005) study that uses a grounded theory methodology to define a value/psychological family-centred approach as placing the needs of the child, in the context of their family and community, at the centre of care and devising an individualised and dynamic model of care in collaboration with the child and family that will best meet these needs:

*'A system of care structured around a medical model that has developed to deal primarily with acute and infectious diseases is a poor fit for both child health care providers and families. In response to these pressures, family-centred care is being increasingly viewed as best practice in child healthcare settings.'*

(Mackean *et. al.* (2005) p. 75)

Six key themes are most frequently described in Mackean *et. al.*'s (2005) study, recognising the family as central to and/or the constant in the child's life, and the child's primary source of strength and support (1), acknowledging the uniqueness and diversity of children and families (2), acknowledging that parents bring expertise to both the individual care-giving level and the systems level (3), recognising that family-centred care is competency enhancing rather than weakness focused (4), encouraging the development of true collaborative relationships, between families and health-care providers, partnership (5), facilitating family-to-family support and networking, and providing services that provide emotional and financial support to meet the needs of families (6). There are close links here to the work of Kitwood (1997), and Nolan *et.al.*(2004) discussed in chapter 2 p. 30 in the way that relational care has begun to be explored in dementia care.

Further, the literature that has developed regarding dementia and palliative care suggests a blended approach to care recognising that dementia is a terminal illness (Birch and Draper 2008). The philosophy of palliative care advocates the relief of suffering, improvement to quality of living and dying, for people with life threatening illnesses and their families. Palliative care addresses the physical, psychological, spiritual, social and practical issues of living with a live threatening illness (Ferris *et. al.* 2002).

Shelton *et.al.* (1987) explored what elements of value/psychological family-centred care the nurse could identify in her practice, i.e. information giving and sharing of care plans or patient records. Shelton *et.al.*'s (1987) study found that nurses' education or experience did not relate to their perception of the key elements of a value/psychological family-centred approach, a finding that resonated with later studies by Friedmann (1989) and Hallgrimsdottir (2000). This dilemma provided a barrier to the implementation of a value/psychological family-centred approach as nurses traditionally use the nursing process as a helping role to determine, and evaluate, the patient's problem, the appropriate interventions and the expected outcome. The process is controlled by the nurse as the family is not seen as responsible for the problem or the solution. Adams (36: 2005) provides evidence of similar practice in dementia care. The philosophy of a value/psychological family-centred approach takes a blended person centred and relational approach that is based on strengthening family functioning enhancing and self efficacy within the family (Dunst and Trivette 1996).

Newman (1994) moves the value/psychological approach away from 'theories of nursing' by using the value/philosophical approach to identify the values, attitudes and feelings of the family rather than working from the base of a nursing framework. Each family member's meaning in the family's pattern is assimilated into a mutual meaning. Meanings may be immediate primarily from one family member or develop over time. Mutual meaning of events increases the caring and action potential of the family and each family member expresses caring towards others and desires actions to share within the family. Transformation then occurs; this is the action of the family's expression in changing circumstances and realisation of self growth. Each phase can overlap and take different periods of time, it is a non-linear process, but none of the phases are excluded (Newman 1994).

Whyte (1997) goes on to develop the work of Newman (1994) highlighting the necessity for a truly collaborative relationship between the family and health care provider. Although technical competence, diagnostic and treatment skills and up to date unbiased information were all expected by parents, it was the relational competency of the healthcare provider that dominated the descriptions of parent's experiences with the healthcare system. The most frequently described were caring, communicating with parents and interacting with children. Caring encompassed being compassionate, respectful, and providing care in a personalised way. Parents not only valued these skills, but also the collaborative way health-care providers went on to develop a care plan that would best meet the needs of the child and the family. Hellstrom *et. al.* (2005) supported these points and also found that a sensitive approach to information giving and support at point of diagnosis in dementia care strengthened the patient carer relationship.

Keady and Nolan (2003) have further developed the work of Kitwood (1997) to explore how couples overcome the challenges of diagnosis (chapter 2 p.30). Hutchfield (1999) notes similarities in the children's literature when examining partnerships, parent participation and a 'holistic approach', a philosophy that supports parents in their role of shared care. She particularly highlights the need to further explore aspects of collaboration, negotiation and co-operation as these dimensions were not always evident in the care received by the child and their family. She suggests that a next step could be the beginning of a value/psychological based approach to family-centred care.

Further, in a co-relational study based on family stress theory, Saunders (1999) made some interesting conceptual definitions of a family-centred approach that are developed in the

exploration of caring partnerships and pattern recognition by Emiko *et. al.* (2003). Here, a value/psychological family-centred approach is developed from re-constructing interventions with family coping behaviours, family psychological distress, family social support, patient behavioural problems and family functioning. The study recommends more family orientated research to help improve family functioning behaviours to reduce psychological distress. This literature would appear to correlate with the literature highlighted in the contextual chapter 2 of this thesis. The long-term outcomes of Emiko's (2003) study were beneficial to the carer as well as the person receiving care. Nurses were able to develop effective intervention strategies following the use of this approach going onto help families cope with the stress and strain of caring for a family member with a severe mental illness. This further identifies the need for a nursing approach that not only provides an intervention but builds a relationship that includes partnership, trust, and empowerment (Brodaty, Green and Koschera 2003).

Sohlberg *et. al.* (2001) provide evidence that a preliminary model of clinical characteristics that are requisite to forming value/psychological family-centred approaches to include collaborative working with families and clinical expertise, role replacement and interpersonal skills. In this study a survey of parent's reactions to practitioner's behaviour suggested clinicians who displayed self-confidence and seemed well informed were regarded favourably by parents. Role release is a term used for the process of learning from and teaching other members of a group so that expertise is shared across family members. For example, role release setting goals in rehabilitation. Sohlberg *et. al.* (2001) expands the notion of 'expert' to include families and it increases the likelihood that family members will participate in treatment and therefore improve the outcome. Being a skilled communicator is also an

essential element of collaborative practice, this in turn facilitates empowerment (Sohlberg 2001).

In 2004 Franck and Callery proposed a re-thinking about how family-centred care in children's nursing is developed, as the research and application to practice remained unclear. Their work provides valuable pointers for this thesis. They identify 'constructions' of family-centred care. The major constructions being respect, the importance of the family to the child's wellbeing and partnerships between the professional and the child/family. Further constructs are explained in terms of related concepts, child and family empowerment, the importance of the family for the wellbeing of the child is recognised and demonstrated by evidence of support to the family in providing for the child's healthcare needs, child/family friendly healthcare services and shared decision making in healthcare representing partnerships between healthcare teams and family/child. Further sub-concepts may be required to link empirical knowledge indicators, for example, family function can be directly measured by empirical indicators of family stress or conflict. Franck and Callery (2004) also suggest that the void between practice and the scholarly world are difficult to join, the practice can fail to live up to the theory and the theory and practice require very different types of knowledge. They conclude that efforts to promote family-centred approaches in practice would be enhanced by theory that emerges from practice (Franck and Callery 2004). It appears that emerging theory from the nursing and dementia care literature is salient and will be further explored in the following chapters of this thesis.

## **Summary**

It would appear that a family-centred approach at this early stage of this thesis holds a

resonance with Admiral Nurse practice. The literature indicates that a blended family-centred approach that includes person centred, relational, palliative approaches may hold meaning to carers (Kitwood 1997; Ferris *et. al.* 2002; Keady and Nolan 2003). There is evidence in the literature that a family-centred approach would include the support of psychosocial interventions, assessment, implementation and evaluation based on the theories that are familiar in nursing (Orem 1985; Rogers 1970). The nurse will however require the practice skills necessary to recognise the central role of the family. Additionally family strengths and capabilities (Shelton 1987; Friedmann 1989; Hallgrimsdottir 2000). Sohlberg (2001) and Whyte (1997) indicate that practice skills are required that can support not only technical skills in intervention terms but leadership in the terms of recognition of carer expertise, collaborative working with family members and other professionals, communication skills and knowledge should all contribute to a family-centred approach.

These suggestions resonate with the psychosocial intervention literature examined by Brodaty, Green and Koscera (2003) at the beginning of this chapter. The question remains whether without a continuous relational support by a professional; the carer can retain recognition of their relationship with the person with dementia and wider family relationships. Can carers find meaning to their relationships when implementing coping and behavioural strategies (psychosocial interventions). This literature review suggests that the family-centred approach of Admiral Nursing has that meaning and utility to carers.

In light of the historical stigma and lack of awareness of dementia care, careful consideration is now given in Chapter 4 to the implications of the use of research methodology and methods (Harding *et. al.* 1997, Brown 1995).

## **Chapter 4**

### **Methodology**

#### **Introduction**

I discussed in Chapter 1 how the impetus for this study emerged from my own life experience and working with people with dementia and their family members. In Chapters 2 and 3 areas within the discussions of the context and literature I have pointed to an uncertainty about the use of psychosocial interventions that do not simultaneously develop a family-centred approach that has a meaning for carers. This has motivated me to focus this inquiry in the pursuit of advancing knowledge whilst furthering my understanding of the research process.

Accordingly working through research methods, approaches and processes has become as important as the inquiry. The background and theoretical approach to appreciative inquiry is now described followed by a discussion of how the approach has developed as a research methodology. In keeping with this I begin this chapter with a brief overview of the philosophical debate from a ‘Freirean’ perspective. The chapter continues with a description of appreciative inquiry which is paralleled with an action research approach. The social construction of dementia discussed in Chapter 2 and my reflexive account of dementia care in practice (Chapter 1) led me to begin this thesis by underpinning how appreciative inquiry’s base in social construction is particularly important to this research given the lens through which dementia has been socially constructed over the years (Harding *et. al.* 1997, Brown 1995).

The theoretical base and rationale for a variety of methods for data collection are discussed (questionnaires, interviews, photography and narrative, focus groups, mind mapping and nominal group technique). The chapter includes with a discussion that supports constructivist constant comparison analysis. The discussion describes the underpinning analysis framework for this thesis that builds on the work of Reed (2007) developing a constant comparison technique as the framework of analysis.

## A ‘Freirean’ Approach

As a nurse I have become increasingly interested in how dialogue is used as a means towards self-knowledge and social awareness. As illustrated in Chapter 1 through my personal experiences and nursing practice, I strive to see the connections of how dialogue through action and reflection link individuals to the larger whole of society. Collaborating together socially and/or in peer groups I see how it is possible to make connections to support individuals to learn more about themselves and each other. Psychologist Jerome Bruner (1986) claims that people can use words to change their lives. The education scholar Paulo Freire (1972) takes a similar view linking action and reflection with change:

*‘Human existence cannot be silent, nor can it be nourished by false words, but only true words, with which men will transform the world. To exist, humanly, is to name the world, to change it. Once named, the world in its turn reappears to the namers as a problem and requires of them a new naming. Men are not built in silence, but in word, in work, in action-reflection’.*  
(Freire 1972 p. 61).

It is by engaging in dialogue that men and women are humanised. Words are not a mere expression of thought; they are a transformation of praxis, which acts upon the world, (Freire 1972, p. 61).

According to Freire's 'dialogical action theory' in the process of domination the subject conquers another person and transforms them into a 'thing', the dialogical process has a dialectic feature in that one does not annul another. When meeting in dialogue subjects meet in co-operation to transform the world. He was opposed to education made by 'oppressors' which he referred to as 'banking' education whereby the teacher becomes the 'depositor' and the pupil as a depository. Instead of communicating the teacher issues communiqués which students patiently receive, memorise and repeat described as 'banking' (Freire 1972).

Paulo Freire has remained, since the 1960s, a powerful influence among those developing theoretical and practical alternatives to development approaches with the carefully developed concepts of 'conscientisation' and 'dialogical education'. In other words a participatory and inclusive approach to research (Nye 1998). Prior to the use of the word 'participatory' it was common to use the phrase 'Freirean' to describe a 'bottom up' or 'grass roots' approach. Paulo Freire approached the problem of education and by implication, human development, primarily from a philosophical angle. He used evidence of underpinning influences from the phenomenology of Husserl, existentialists like Barber and Sartre, Christian and Marxist humanists like Macuse and Schaff and the psychoanalytical theory of Fromm (for more information see Blackburn 2000). Freire developed an educational methodology to facilitate a process of conscientisation that is; making people more aware and engaged with their world. Through action people (the under privileged of Latin America) could create a new situation making it possible to pursue fuller humanity. I would interpret the fuller humanity as leading to a person's 'wholeness' of self hood. Self hood whilst different for everyone means resolving the 'power' differential between social classes, solving family conflict or feeling at peace with oneself.

Freire's method of inquiry involved two stages. In the first stage the 'oppressed' discover and 'unveil' their oppression and commit to transform it. In the second stage, individuals teach each other. Freire (1972) stated that it is not possible to educate for critical consciousness without the dialectic process, which involves dialogue between individuals. For Freire anyone could educate anyone, men and women are educated by each other, mediated by the world (Freire 1972). They do this by becoming involved in their own organisational struggle for 'liberation' that must involve action. A process of reflection joins and mediates the theory requiring dialogue between the oppressed and the oppressors (Nye 1998).

Freire achieved great success in the world of education but was not without his critics. In his book *Pedagogy of Hope* (Freire 1994) he defends his progressive views and directly responds to criticism of his work regarding sexist language and pompous writing style. He expands on his conception of oppression to include race and gender oppression emphasising his commitment to pedagogy of political education though his vision of antisectarian and antiauthoritarian practices of education (Santos 2008).

Examples of Freire's philosophy can be found in community settings. In 1993 Kathy Boudin an inmate and teacher in a New York prison applied a liberatory approach to address the issue of Acquired Immune Deficiency Syndrome (AIDS) in a literacy programme. Boudin found that reading and writing instruction in the prison was boring and irrelevant to the inmates. Yet Boudin (1993) found that the inmates shared a real fear of AIDS which created a collective silence and need to talk. The outcome after a Freirean approach was adopted was a written handbook for future inmates and the students wrote together and performed a play. Nye (1998) developed a writing group with Jewish elders encouraging the development of memory and

life story narratives and poems. By adopting the Freirean philosophy she found the members of the group did not radically change their lives but continued to meet after the study finished. Each group member was able to identify a sense of wholeness, developing a sense of connectedness self consciousness contrasting with Boudin's (1993) powerful action related results.

## **Background to Appreciative Inquiry**

The choice of methodology for this thesis has been led by Freirian philosophy and interest in action research because of its participatory nature. More recently the concept of action research has been developed in the social sciences into action research as an intervention methodology, to increase the understanding of the research situation and at the same time pursue change. First introduced by Kurt Lewin (1951) just after the Second World War it was used in conjunction with his search for methods that were suitable for dealing with social problems. It has since continued to be used to promote organisational change and development (Robson 2002). Change and understanding, action and critical reflection alternate within a cyclical process. The understanding and change enrich each other (Roberts and Dick 2003). Lewin viewed action research in a similar way to Freire when viewing the oppressors of education as a burden to democracy. Interestingly his first focus groups were aimed at convincing homemakers to use less meat during war time, which was somewhat limited in its democratic approach. This merging of activism and research with the empowerment of women has been central to many researchers, including feminist researchers. More generally it has been seen as a means for fighting oppression and social injustice (Robson 2002 p. 216).

During recent years action research has gained increased interest in health care research as a potential approach to developing this complex field (Coghlan and Casey 2000; Boog 2003; Roberts and Dick 2003; Nomura *et. al.*; 2007 and Chang *et. al.* 2009).

Action research involves interpreting and explaining social situations while implementing a change intervention. Action researchers adopt a participatory approach involving participants at each stage of the research process. Action research is an approach rather than a specific method of data collection. It involves doing research with and for people in the context of application rather than doing research on them. There are three broad types of action research; technical-scientific and positivist research, mutual-collaborative and interpretivist action research and critical and emancipatory research (Robson 2002). The mutual-collaborative and interpretivist action research approach is the most common approach used in nursing. As in appreciative inquiry it involves bringing together researchers, policy makers, service users, health care providers and stakeholders to identify potential problems, try out solutions and monitor the process and outcomes of change (Gerrish and Lacey 2006).

Exploration of this concept of participatory research led to one related approach used in organisational change, appreciative inquiry. Appreciative inquiry is a relatively new research methodology that allows exploration of concepts and models from a position which focuses on achievements in practice. The use of appreciative inquiry has the advantage of allowing for creative engagement with participants, it has been widely used in organisational change and offers constructive analysis (Reed 2007). Making the choice to use appreciative inquiry will allow the participation and collaboration of a wide range of cognitive ability, skills and experiences of the participants' who will contribute to the thesis.

Appreciative inquiry is about discovering and applying new knowledge/new ideas about key

aspects of organisational life (Hammond 1991; Hammond and Mayfield 1991; Cooperrider and Whitney 1999). Appreciative inquiry was first used in the United States as an approach to organisational change. In particular it focuses on generating and applying knowledge that comes from moments of excellence, periods of exceptional competence or performance. Examples of applications of appreciative inquiry include productivity, innovation, strategy development, customer service, business process design, diversity evaluation, organisation culture and leadership, this is by no means an exhaustive list and appreciative inquiry has many more viable applications (Whitney and Trosten-Bloom 2003). In the context of this thesis it is a research methodology. As a relatively new research methodology it is simply a radical approach to understanding the social world. It concentrates on exploring the ideas that people have about what is valuable in their daily lives or in what they do and then tries to work out ways they can be built on (Reed 2007).

The work of Kitwood 1997 and the drive of national policy discussed in chapter 2 have begun to influence changes in dementia care practice, for example the relationship approaches to care of the person with dementia and their carers' of Keady and Nolan 2003 Keady *et. al.* 2004, and, the increasing demographic rise in the incidence of dementia (DH 2007; DH 2009).

Thinking about how to use appreciative inquiry in the research process I needed to be able to extend and magnify my views of what family-centred Admiral Nursing means to carers. My aim was to find a method based on an action research method with a Freirian philosophy that enabled me to see the world from my participants' view point without appearing to be judgemental or assuming about their day to day lives and practice.

The underlying assumption of appreciative inquiry is not a ‘problem to be solved’ but rather a ‘solution to be embraced’. The steps are valuing, envisioning, dialogue and constructing the future. Interestingly the steps are similar to those identified in the family-centred approaches literature (Friedmann 1989; Whyte 1997). Valuing the best of an experience, leads to envisioning ‘what might be’ a positive image of a desired future based on this valuing. Engaging in dialogue with participants is the path to sharing discoveries and possibilities. A consensus emerges where an individual appreciation evolves into a collective appreciation. The final step is the construction of the future through innovation and action (Cooperrider *et. al.* 2005). Because these ideals are grounded in their realities participants have the confidence to try and make things happen.

Appreciative inquiry involves a cyclical process focusing the attention of the research study on its most positive potential, unleashing the energy of the positive core for transformation and sustainable success. It is not a linear process that stops when completed but a process that never ends as the steps are repeated and continued learning and revisiting are part of the process. There are two typologies of the appreciative cycle outlined in the literature. Cooperrider and Whitney (1999) provide the 4 ‘D’ cycle: discovery, dream, design, and destiny. Mohr and Jacobsgaard, cited in Watkins and Mohr (2001) put forward the 4I model: initiate, inquire, imagine and innovate. Both follow the basic second dimension of action research proposed by Cooperrider and Srivastva (1987). The 4 ‘D’ cycle illustrated is the most well known appreciative inquiry framework (Reed 2007). The 4 ‘D’ cycle begins with an affirmative topic choice and becomes the subject of learning and innovation. This is the frame of the inquiry for this thesis.

The process of appreciative inquiry is ongoing and does not stop with the formal ending of the research study but can continue to develop recommendations, ideas and aspirations of each participant(s) and organisation. Appreciative inquiry works in a way more familiar with an action research approach using a participant led methods, allowing for the flourishing of the art and craft of the data to develop a change of lens throughout the period of data collection (Reed 2007). Using appreciative inquiry has meant that the ways of collecting data can be extended in scope allowing for the creative and artistic participation to flourish. This was a fundamental consideration to the choice of appreciative inquiry as a research method in this thesis. Appreciative inquiry does not fit any one research method exactly or exclusively, it shows different characteristics that can be compared to range of methodologies (Reed 2007).

*'Appreciative Inquiry focuses on supporting people getting together to tell stories of positive development in their work that they can build on.'*

(Reed 2007 p. 47)

Whilst appreciative inquiry is the methodology for this study a variety of research methods, questionnaires, interviews, photography and narrative, focus groups, mind mapping and nominal group technique have been interwoven within it to form a participatory base for the inquiry. Using a variety of research methods will help to inform the research in a number of ways. For example, supporting people by engaging with them to facilitate the active input of those exploring the change, it is communal, collective experiences are shared and explored telling stories and positive developments that focus on change and plans for the future are developed (Frederickson and Levenson 1998; Frederickson 2003; Frederickson and Losada 2005).

## **Using Appreciative Inquiry as a Research Methodology**

Grant and Humphries 2006 critically review the use of appreciative inquiry as a research method. They found that although its visibility has increased in recent years applications of appreciative inquiry as an action research method have a limited range for example in schools (Van Buskirk 2002; Price *et. al.* 2007) and in the community (Carter 2006) .

Bushe (2007) argues that appreciative inquiry is in danger of being used for organisational change and simple content analysis of interviews. This, Bushe, argues, is not how the stories should be used and therefore is not a practical or useful research method. However there is, he argues, a ‘provocative’ possibility embedded in the idea that appreciative inquiry can be used to study social innovation or the ‘positive change core’ which in turn invokes ‘what could be’ (Cooperrider & Srivasta 1987; Cooperrider 1990). He critiques the studies by Reed *et. al.* 2002 and Yoder, 2005 highlighting the use of appreciative inquiry to focus on a) bringing multiple agencies together, and, b) content analyse interviews. He does not however consider Cooperidder and Srivastas (1987) original development of appreciative inquiry to be used as a complement to conventional action research. On the other hand Van der Haar *et. al.* 2004 emphasise that other developments have been made in action research that give particular emphasis to collaboration. Manley *et. al.* 2005 provides the example of when there is a need for an affirmative approach to research to remain central to the sensitive nature of the inquiry.

Appreciative inquiry has its base in Gergen’s socio-rationalist paradigm which treats social and psychological reality as a product of the moment, open to continuous reconstruction (Bushe 1995). Van der Haar and Hosking (2004) evaluate appreciative inquiry from a relational constructionist perspective arguing the constructive role of this relational ‘thought’

style. Van der Haar and Hosking (2004) support appreciative inquiry they argue that it facilitates multiple local constructions, recognising that reflecting moments are part of the social construction process. They highlight that listening to different constructions, and dialoguing what strengths and values people want to build on can be seen as a moral, and critical practice, that is sensitive to, and tries to work with, power relations in ways that facilitate ‘power’ to go on in different but equal relations (Van der Haar and Hosking 2004). On the other hand a critical evaluation of appreciative inquiry by Grant and Humphries 2006 urges caution on the potential tensions between the intentions of critical theory (for example scepticism and exposure to abusive power) and appreciative inquiry (for example inspiration). Van der Haar and Hosking 2004 and Reed 2007 support this highlighting that given the relational constructionist premise, it is important to appreciate that what is ‘positive’ is also a variable local construction. For some to rule out critical reflection may be experienced as negative by the person imposing his/her reality on others (Reed 2007). Grant and Humphries 2006 suggest a combination of the two, explicitly focusing researcher and participants on emancipatory ideas to provide fruitful contributions to the action research process that is sensitive to, and tries to work with power relations in ways that facilitate ‘power’. The aim in this thesis is to use appreciative inquiry to actively encourage the ‘voice’ of the carer.

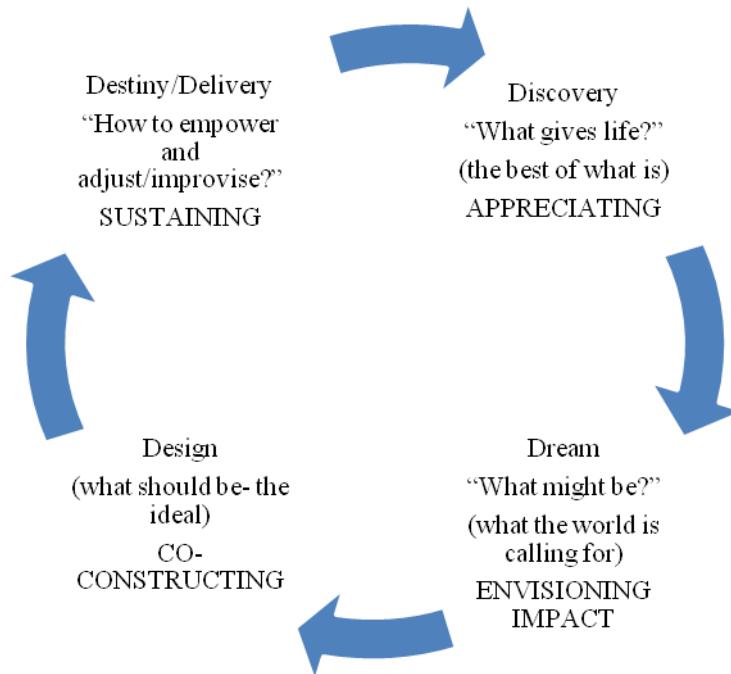
## **Appreciative Inquiry - how it works**

The history of appreciative inquiry lies with the experiences of David Cooperidder, who, whilst studying a doctorate on organisational dynamics (completed in 1986) took a different approach from the established methodologies of organisational research (Reed 2007). Cooperrider interviewed doctors in a hospital in the United States. He found that asking

questions about their work that invited them to describe and discuss aspects of their work they valued appeared to encourage them to talk in an unrestricted way (Reed 2007). The basis of inquiring in an ‘appreciative’ manner had been born (Reed 2007). Following the completion of his doctorate Cooperrider and others have refined and developed appreciative inquiry across a range of organisations and contexts (Reed 2007). Watkins and Mohr (2001) describe this process as a timeline from 1980 to present day.

The processes of appreciative inquiry have been recognised as ‘cycles’ (figure 2). The cyclical nature of the appreciative inquiry process points to the iterative nature of appreciative inquiry, it is not a linear process that stops when it is completed (Reed 2007). It is a process that continues as the steps are repeated (Reed 2007). Cooperrider *et. al.* (2005) cautioned, however, that appreciative inquiry should not be seen as a set of cyclical procedures, but, stems from, the positive core that is made up from the, strengths, goals and achievements of the organisation.

**Figure 2 The Appreciative Inquiry Cycle (Cooperrider *et. al.* 2005)**



## **The 4 'D' Cycle**

### ***Discovery***

One of the most important things to do as a researcher using appreciative inquiry is to develop the inquiry. The questions that are asked and the topics chosen to focus on determine what is found. The findings in appreciative inquiry become the data and the ‘story’ out of the dialogue is the vision for the future (Cooperrider *et. al.* 2005). This is where the inquiry begins. It is important to craft and ask unconditional and powerfully penetrating questions to draw out the best creativity and vision from all. Collecting useful, positive and appropriate data using research methods that are participatory, for example telephone interviews and focus groups is key to the success of the discovery stage (Cooperrider *et. al.* 2005).

### ***Dream***

*‘Human conversation is the most ancient and easiest way to cultivate conditions for change’.*

(Wheatley 2002 p.7)

The dream stage is an invitation to participants to amplify the positive core of data collected when using a range of research methods for example focus groups and mind mapping. Using a range of creative research methods the participant is enabled to imagine the possibilities for the future that have been generated through the discovery phase. The dream stage is traditionally practical and grounded in the research inquiry, and generative in that it seeks to expand the data to its full potential. The methods of data collection should seek to challenge the status quo with an intention to create synergy and excitement. Once the data collection methods generate ‘a spirit’ and acknowledgement of the possibility of positive outcomes and recommendation the positive core can be channelled, focused and used to design how it will be creating the destiny of the envisioned dream (Cooperrider *et. al.* 2005).

The aims of the dream stage are to facilitate dialogue among the participants in which they share positive stories in a way that creates enthusiasm and energy for future developments, as they dream of possible goals, structures and processes. Firstly, it is important to record the whole story so that it can be shared by all the participants bringing out the positive core of the research inquiry. The second aim is to allow the participants to start to see common themes. At this point it is important to encourage the participants to observe and value the data rather than criticise, judge and analyse the data.

Evidence that positive emotions enhance wellbeing supports the appreciative inquiry framework. Positive psychology is the basis for appreciative inquiry and psychologists such as Frederickson have been drawn to the study of positive emotions. This is not an isolated case as studies by Seligman in the 1940s coined the phrase ‘learned helplessness’ to describe the

hopelessness and other negative emotions that can spiral down in depression (Frederickson *et. al.* 1998; Frederickson 2003 and Frederickson *et. al.* 2005). Reed 2007 however advises that problems and concerns can also provide a rich data source and should not be ignored.

The objective of the dream stage is to support the participants to imagine things how they would like them to be, by building energy, and synergy, extracting common themes or ‘life giving forces’ the participants can start to envisage the future. The crafting of questions and methods of data collection in the dream phase has important significance to elicit the quality of data required to identify themes that will become the starting point for the design stage of the 4 ‘D’ cycle.

Many of the previously used dream activities share common components (Whitney and Trosten-Bloom 2003). They take place as soon as possible after the discovery stage; involve large groups of people; start to energise people (i.e. guided visualisation, group activities); they use a focal question (facilitator selects the question, along with an appropriate time frame for individual and/or group discussions); the groups or individuals move into group discussions with no more than 12 to a group.

### ***Design***

Cooperrider *et. al.* 2005 describes the design stage by using the analogy of building. An architect considers many elements in their design, a foundation, a roof, walls, windows, doors and floors. Within the constraints of these elements the architect will have choices in which to accommodate their unique preference. For example they may choose a glass roof, a brick or cement exterior. Designing provocative propositions is a kind of social architecture; it addresses the design elements critical to the data for example, systems, structures and

strategies. Cooperrider *et. al.* 2005 suggests four design steps: selecting the design themes (1); identifying internal and external relationships (2), identifying themes and engaging in dialogue (3) and writing provocative propositions (4).

The design themes (1) can be chosen by the participants as cited in Cooperrider *et. al.* 2005 p.143 or selected by the core team. Each element is taken into consideration when implementing a new strategy large or small. They are interdependent so if one is ignored it can affect the others as well. The design stage defines the basic structure of the data that allows the dream to become a reality. Like all the stages in the 4 ‘D’ cycle design requires dialogue about the nature of processes and structure. In this study there was an overlap with dialogue from the dream stage using focus groups to develop the data. This was necessary due to time constraints and the nature of the geographical area of the study.

Once the themes have been developed the next step (2) is to identify the relationships that helped to build the positive core. The key relationships (3) are listed and used to design the provocative propositions. The writing of provocative propositions (4) in academic research is traditionally completed by the researcher using coded data and field notes. Miles and Huberman 1994 recommend this as there is a greater need to formalise and systemise the researcher’s thinking into a coherent set of explanations. An illustration of provocative propositions developed in this was can be found in Stearns *et. al.* 1980. A description of how this work has been adapted for this study can be found in Chapters 6 and 7.

### ***Destiny***

The final stage of the 4 ‘D’ cycle is destiny sometimes known as delivery (Cooperrider, *et. al.* 2005). The goal of this stage is to ensure that the dream can be realised. It emphasises the need

for continuing learning, adjustment and improvisation. The techniques associated with this final stage are self organised and often reassemble the processes of the study. An imposed sequence of leadership or management should not be prioritised. Instead there should be a natural lead from the participants who wish to participate in future developments. It is a time for continuous learning and adjustment that will possibly re-visit the 4 ‘D’ cycle in developing aspects of the research findings.

## **Methods of Data Collection**

Whitney and Trosten-Bloom (2003) recommend a period of reflection and consideration when choosing forms of engagement when using appreciative inquiry. Different inquiry strategies should best suit the needs of the context of the study and thought should be given to how the participants will be able to engage with them. An inquiry strategy is recommended by Whitney and Trosten-Bloom (2003) to describe how each engagement will take place and in which form.

**Figure 3                          Methods of Engagement**

Preliminary Stage	Discovery	Dream	Design	Destiny
Involves crafting the appreciative inquiry interview guide(s), conducting interviews making sense of what has been learned.	Involves individual and collective visioning, group dialogues, and enactments of positive images of the future.	Involves collaborative identification of the participant's social architecture and crafting of provocative propositions describing the ideal.	The unleashing of the participants' innovation.	Placing in context of social research analysis and dissemination of findings.
Search & Interpretation of the literature	Strand 1 Telephone interviews	Strand 1 Photography and narratives	Strand 1 Focus Group	Reference Group
Questionnaire	Strand 2 Focus Group 1 Using mind mapping	Strand 2 Focus Group 2 Using nominal group technique	Strand 2 Focus Group 3	Reference Group

Each method of engagement has been introduced to meet the four stages of the appreciative inquiry cycle (4 ‘D’ cycle: discovery, dream, design and destiny) as illustrated in figure 3 (adapted from Whitney and Trosten-Bloom (2003) p. 49). The methods of engagement are supported by the methods of data collection questionnaire, interview, focus groups, mind mapping, photography and narrative and nominal group technique. A preliminary stage has been added to the 4 ‘D’ cycle for the purpose of crafting the questions for the discovery stage. The 4 ‘D’ cycle has been further developed to include two strands in the discovery, dream and design stage to develop transparency of the two consecutive parts to the study (carers group and Admiral Nurse practice). In the design stage of the study data from strand one and two are contextualised, analysed and implications for practice described. Each strand is discussed in depth as part of the 4 ‘D’ cycle in chapters 6, 7 and 8.

### ***Questionnaire***

Questionnaires are commonly used in research and most people will be familiar with taking part in some form of questionnaire completion. The concepts to be collected were going to be the building blocks of theory to this thesis and represented the point where the social research part of the study could begin (preliminary stage). Bulmer (1984) phrases this as, ‘concepts are categories for the organisation of ideas and observations’. Ascertaining these concepts at the beginning of the study gave a qualitative base line that could be analysed. They also provided an explanation for certain aspects and ways Admiral Nurses worked before the study began to provide data to craft the appreciative inquiry questions for the discovery stage of the 4 ‘D’ cycle.

A questionnaire was the chosen research method for the preliminary stage to the 4 ‘D’ cycle. This was primarily for ease of access to the participants and acknowledgment to the amount of

time they would have to give to the study, and, to introduce the interactive and participatory nature of appreciative inquiry. Questionnaires have the advantage of being completed by the participant without the interviewer asking the questions. This does impact on the type of questions that are asked as they necessarily have to be easy to follow, and particularly easy to answer and facilitates measurable responses (Boynton 2004). Interviewing can be expensive in terms of time and travel. The cheapness of the self-completed questionnaire is undeniably advantageous as in the case of the preliminary stage of this study the geographical area is widely dispersed. The choice of questionnaire is much cheaper in this case, because of the time and cost for the researcher to travel. Comparisons can be made with telephone interviews, but the cost of using a postal questionnaire is another advantage (Boynton 2004). The disadvantages of using a questionnaire were carefully considered as they can be time consuming for participants, the answers have to be coded which can be time consuming and it can be perceived by the participant that they require a greater effort that can exacerbate low response rates.

The self completed questionnaire is known as the self-administered questionnaire. Probably the most well known of these forms is the postal questionnaire, where as its name implies the questionnaire is sent through the post to the respondent. Following completion of the form the respondent is asked to return it in the post. Alternatively, respondents are requested to deposit their completed questionnaires in a certain location. The term ‘self completion questionnaire’ denotes a questionnaire that is handed out by the researcher to all participants and then collects them back when they are completed. Robson (2002) recommends more than 15 participants when using a questionnaire. Typically quantitative and qualitative data are collected often using a type of scale for both explanatory and outcome variables.

Measurement allows the delineation of fine differences between practices enabling the distinguishing of practice methods in terms of recognising fine distinctions. Measurement provides a consistent device for making such distinctions. In order to provide a measure of a concept (or *operational definition*, Bryman 2004) it is necessary to have indicators that will stand for the concept. There are a variety of ways in which indicators can be devised. Open questions are used to collect qualitative data the advantage being that participants can answer using their own terms and they allow unusual responses that may not have been anticipated. The questions do not suggest a certain type of answer allowing the participant to use their knowledge and expertise in the answer. They are useful for exploring specific areas and they are for generating fixed format answers.

The design was easy to follow to minimise the participant missing or misinterpreting a question and it was relatively short to prevent the participant becoming ‘bored’ or ‘timed out’ as it is easy to consign the whole thing to the waste bin. Questionnaires could be sent out in large quantities in one batch, whereas interviews would require a team of interviewers to conduct personal interviews with a sample as large as in the preliminary stage of this study. This is a resource that was not available the method of data collection also added a dimension to the design of the study giving an opportunity to view the data through a wider lens. Sensitivity to the nature of the data was also carefully considered. It is well documented that various studies have demonstrated that characteristics of interviews and respondents may affect the answers people give (Edwards *et. al.* 2002). The research highlights that characteristics such as ethnicity, gender, social background and experience in the subject matter may combine to bias the information given by respondents (Boynton *et. al.* 2004).

However the literature encourages caution as there is little evidence to suggest what kind of interview characteristic bias answers. Research by Tourangeau and Smith (1996) on sexual preferences and drug use suggests that sensitive information is more likely to be given in a questionnaire without the presence of an interviewer. There is no interviewer variability and questionnaires are not biased or influenced by questions being asked in a different order or with different intonation or emphasis. They have the advantage of being flexible in where and when the participant chooses to complete them (Boynton 2004).

As there is no one available to prompt the participant should they not be able to understand the question therefore the questions in a self completed questionnaire must be kept clear and easy to understand. The questionnaire should also be easy to complete as questions will be inadvertently omitted if the instructions are unclear (Boynton 2004).

The questions in the questionnaire for the preliminary stage of this study were a mixture of open and closed questions. Some closed questions were asked to give a context to the background of each participant which is more unusual when using an appreciative inquiry methodology (Whitney and Trosten-Bloom 2003). These questions were asked to provide a basic context to qualifications, length of service and role. The importance of which is discussed in Chapter 3 in context with nurse knowledge and practice expertise and the application to a systematic family-centre approach (Freidmann 1989). Some replies required comment or a choice of answers using a Likert Scale (Sitzmann 2000).

### ***Interviews***

When connected to appreciative inquiry research the interview or ‘conversation’ has a similarity to appreciative inquiry organisational development work, which focuses on what

works well in a co-operative way (Reed 2007). Appreciative inquiry interviews can be conducted in one-to-one settings, in focus groups or on the telephone. In this thesis two interview methods were used, telephone interviews (discovery stage) and focus groups (discovery, dream and design stages).

Telephone interviews were chosen as the method for the initial data collection with carers in the discovery stage. The one-one interview method was chosen for ease of contact for the carer (there were no travel or respite pressures for the carer) and to allow each carer to tell their story without feeling pressured by group dynamics. In the discovery, dream and design stages a focus group was the easiest and most convenient interview technique for participants to contribute to the data collection. A fuller description of each interview method is set out below.

### ***Telephone Interviews***

Whitney and Trosten-Bloom (2003) suggest nine key components to the appreciative inquiry interview. These include preparation by the interviewer that includes knowledge of the subject, crafting of the questions, and the distribution of an interview guide to the participants. Kvale (1999) suggest that the historic priority of interviewing making method over skills should be reflected on and remind the researcher that a method is mechanical following of a set of rules to attain a ‘goal’. A qualitative research interview is developed socially by using the interaction of the researcher and participant. The production of data then goes beyond the mechanical following of rules and rests on the skills of the interviewer and their personal judgement of posing the questions when following up the interviewees answers. Kvale and Brinkman (2009) go on to pursue four concepts of research interviewing: Interviewing as

semi-skilled labour where interviews implement an interview guide and adhere to specific procedures in a manner closely monitored and supervised (1). Interviewing as a craft where the interviewer possess a ‘tool box’ of techniques and knowledge of the subject (2). Interviewing requires professional expertise and specialised skills in judgement of the consequences and master theoretical knowledge of interviewing and interview topic (3). Interviewing as an art this involves intuition, creativity improvisation and breaking the rules (4). Interviewing techniques can be unconventional and novel with techniques being used in a personal rather than standardised way giving the interviewer considerably more autonomy (Kvale 1999). Reed (2007) also suggests caution when conducting interviews and recommends a period of reflection on skills and experience before proceeding.

The appreciative inquiry ‘conversation’ or ‘interview’ is most commonly a face-to-face discussion of an issue or phenomenon suggesting an exchange of ideas between two people (Whitney and Trosten-Bloom 2003). In standard methodological texts the interviewing reciprocity is not highlighted in favour of the interviewee with the interviewer conducting the discussion with an interrogative agenda (Robson 2002; Bryman 2004). This method of interviewing traditionally elicits as much relevant information from the interviewee as possible, the adequacy and relevance is determined by the interviewer. This is not a comfortable method of interviewing in collaborative research as it elicits differences in power and control (Reed 2007). Appreciative inquiry interview encourages flexible discussion that adheres to a rigid structure, but does respond to the participant’s concerns. The researcher has the opportunity to learn as well, recognising the experience of the interviewee, acknowledging the problems and anxieties throughout the interview, but gently guiding the interviewee to the value or best of the interview question (Cooperrider and Whitney 1999).

## ***Focus Groups***

Focus groups are also widely used in appreciative inquiry as a method of gathering data. The first book on focus groups was written in 1946 by Merton and Kendall as a result of working with groups during and just after the Second World War (Robson 2002). Today the focus group is widely used in a variety of research settings for example communication, policy and marketing. In health associated research it is often used as a method in conjunction with other types of interviewing for example, Daff *et. al.* 2006; Lambert *et. al.* 2007; Hanson *et. al.* 2008 all use telephone interviews in conjunction with focus group as methods for data collection.

Focus groups were chosen as a method of data collection for this study as they afford the advantage of allowing a free flowing discussion. The researcher can then gain access to what the participants see as important or interesting. However, facilitation of the group is important as too much irrelevant discussion can be counterproductive making for a confusing and frustrating group. It is also important to consider the participant with a ‘small voice’ who without careful and sensitive facilitation can become forgotten. Participants of this study came from wide range of professional backgrounds, cognitive abilities and life experiences. To allow for this, two different methods were adopted within the focus group, mind mapping and an adapted approach to nominal group technique. This was to ensure as far as reasonably possible that the wide range of participants would be able to feel included and able to participate at their own pace. These methods also supported the development of the appreciative inquiry conversations and the development of creativity recommended by Cooperrider *et. al.* (2005).

Focus groups are characterised by using the interaction of the participants to elicit their views and opinions about a subject or issue. Participants respond to the interviewer and to each other, different reactions stimulate debate about the subject or issue with group members responding to each other (Bryman 2004). The discussions develop ideas, problems and questions that the researcher has not thought of, before giving them the opportunity to observe how they make sense of a phenomenon and construct meaning around it. In a sense focus groups reflect the process in which meaning is constructed in everyday life and can be interpreted to be more naturalistic than a one-to-one interview (Bryman 2004). In a focus group the facilitator has to relinquish some of the control to the participants to allow themes and topics to develop and be discussed. This is an important consideration in any qualitative research where the views and opinions of the participants are being sort. In one-to-one interviews the interviewer is rarely challenged with participants reluctant to point out discrepancies or inconsistencies in replies. Focus groups give the participants the opportunity to argue with each other and challenge perceptions and thoughts. This gives the researcher a realistic opportunity of gathering a truer account of what people think, because they are forced to think about and possibly, revise their views (Bryman 2004).

The size and number of groups should be manageable for the size and time restraints of the study. A group of six to ten people is usually regarded as a typical group size but, does have the drawback of participants not attending and the group then being too small. It is almost impossible to control who is going to attend on the day the only way to prevent a small group would be to over recruit (Morgan 1998). However, for groups that are to discuss and develop sensitive topics or the personal accounts of participants a smaller group is advised (Bryman 2004).

The role of the facilitator is to gather the perspectives of the people being studied. To allow this the facilitator's role should not be intrusive and structured. It is common practice to use an interview guide that is given to the participants prior to the group to allow for a period of self reflection and contemplation. This is particularly important in a study of this type when participants are going to be discussing personal feelings and experiences.

### ***Mind Mapping***

Mind mapping is a powerful and creative way of capturing graphic technique that can be applied to every aspect of life but is probably best known in the education and business worlds. It is a useful tool for where improved learning and clearer thinking will enhance performance and or discussion.

With such a wide range of participants in this study careful consideration had to be placed on how each person would be able to contribute to the data collection in a way that they understood and was meaningful to them. Appreciative inquiry lends itself to the use of creative tools (Reed 2007). To test mind mapping as way of developing ideas and recording them I made a design of the research study taking each stage of the study through the 4 'D' cycle enabled me to 'map' what the study may look like as it progressed. I found it rewarding and motivational to see a 'picture' build up of the process and it also enabled me in the early stages as a novice researcher to articulate what the study was about to clarify its aims and objectives. Having found this a motivational and affirmative approach to articulating my thoughts I went on to develop the method for use as a data collection in the discovery stage strand 2. This was particularly important when considering the inclusion of people with

dementia when cognitive difficulties make verbal communication difficult. Mind mapping gave an alternative medium of communication that was inclusive and creative (Reed 2007).

A mind map starts its life as a single sheet of paper with access to coloured pens and sometimes other artistic or creative material. A question, title or image is placed in the centre of the paper, with sub-heading or branches leading off (created as ideas as they come to mind). Each branch then has an associated name or subject to it and can be expanded as the ‘map’ is built up (Buzan 1997). There is guidance to the group or individual for maximising the use of the map, but there are no set rules. Each user or group develop their own map in a way that they wish freely using colour, thickness of lines, creative materials and writing. This allows related ideas, concepts or themes to be linked or integrated with each other supported by group discussion, personal experiences and knowledge (Buzan 1997). Using different colours, images and writing for each category can make Mind Maps powerful tools (Buzan and Buzan 1993). Budd, 2004 describes the use of Mind Maps as an in-class exercise in which participants create a Mind Map for different topics.

### *Photography with narrative*

Appreciative Inquiry rejects the traditional methods of power and knowledge within the research relationship so it was important to use a method for the dream stage (strand 1), that was both participatory and entered into the critical consciousness of each participant. Photography and narrative is increasing in popularity among qualitative methodologies in the study of health, illness and health care and has reflected an epistemological commitment to ways that the participants themselves interpret, give meaning to and make sense of their experiences (Harrison 2002). Expressing feelings and emotions in words is the most common way we are asked to describe what is happening to us (Harrison 2002).

Choosing the use of photographs gave an opportunity to break down some of the barriers words sometimes build. Photographs can help with sharing some of the private knowledge people have that is often disguised when using words. Research has trusted words for many years mistrusting the use of pictures saying that they can raise the question of the relationship between private and public knowledge by transgressing this boundary (Harrison 2002).

Transgressing these boundaries became an important consideration for this thesis as appreciative inquiry requires an approach in the dream stage to allow stories to be shared by the participants allowing for visualisation of the data being collected. Visualisation also acted as a validation to the stories told in the telephone interviews providing a rich and eclectic source of experiences of wellbeing and feeling of value from the participating carers. Schratz and Walker (1994) cited in Prosser and Loxley (2006) p. 237 support this,

*'In social research pictures have the capacity to short circuit the insulation between action and interpretation, between practice and theory, perhaps they provide a somewhat less sharply sensitive instrument than words and certainly we treat them less defensively.'*

Radley and Bell (2007) found that telling a story in a visual image is important for anchoring potential in social practice. They found that by using pictures they not only generated data but

were able to engage more fully with the participants. Further the visual data acted as a prompt to the person's every day life's enabling them to reflect on their physical environment.

However it is important to be cautious as photographs have no meaning in themselves, it is the interpretation that is important, and in this thesis participants were asked to write a narrative for each of their chosen photos (Becker 1995). Prosser (2006) p. 247 states that in the action research context photographs become an instrument for change because the photo documents are harder 'facts' of individual expression.

Harrison (2002); Chaplin, (1994) and Harper (1996) found the absence of the use of visual methodologies in social research surprising. Not only because of the ubiquity of visual images we encounter on a day to day basis in a wide variety of social contexts, but also we use visual skills and cues as a taken for granted way of being in the world. Additionally much of the routine work of health and social care practitioners relies on their skills of observation. I would support this with the observation within this thesis that expressing emotion is very difficult and can be easily misconstrued for example; an expression of grief is often misconstrued as anger and taken personally by the recipient of the dialogue (Hibberd *et. al.* 2008). To be able to access the critical consciousness of the participants and at the same time empower them to reach that level of development the work of Wang,(1996); Wang, (1999) and Aubeeluk and Buchanan, (2006) was adopted. This approach of using cameras is sometimes known as ‘photo voice’. Wang and colleagues (1996 and 1999) use of ‘photo voice’ was connected to a women’s health project in China and Aubeeluk and Buchanan (2006) used ‘photo voice’ to explore the concept of quality of life in Huntington’s Disease carers. ‘Photo voice’ was found to be a holistic approach to gaining a picture of Huntington’s disease caregiver role allowing the opportunity to describe the negative and positive aspects of their role (Aubeeluk and Buchanan 2006).

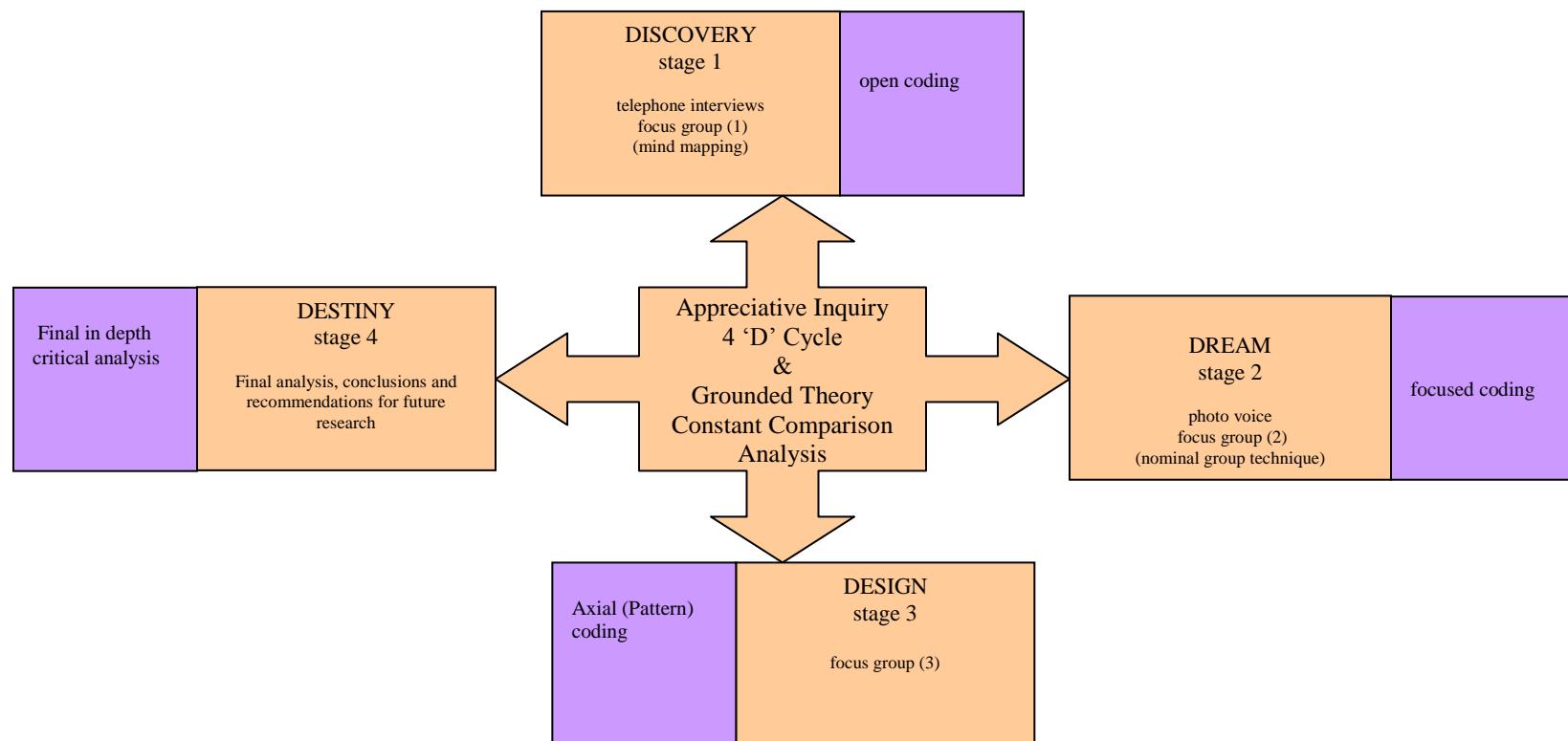
### **Nominal Group Technique**

Nominal group technique is a qualitative approach driven by the opinions and needs of the participants and not by the perceptions of the researcher. It gives an opportunity for each individual to participate and is used frequently in research either to elicit concerns or as a means to establish priorities. An adaptation of this technique was introduced into the focus groups during the dream stage strand 2.

Originating from work developed by Delbecq, (1986) as an organised planning tool nominal group technique has been further developed and is now widely used in healthcare settings and for the evaluation of education (Auster and Wylie 2006; Delbecq 2007). When considering its use in conjunction with this study two studies were considered. Tuffrey-Wijne *et. al.* (2006) used nominal group technique with a group of people with learning disabilities to elicit their views on end of life care provision. They found that the use of nominal group technique was advantageous in this sample group as it followed a structured methodology and avoided the opportunity for one individual to monopolise the discussion. They found the single question technique successful due to its unambiguity and use of a picture with the question improved the inclusivity of their participants. Illiffe *et. al.* (2005) used an adapted nominal group technique with groups of general practitioners to meet resource and pragmatic reasons showing how the method can be flexibly used with different participatory groups and environments. There are four stages to nominal group technique, listing; recording; collating and prioritising. The listing stage is designed for silent construction and development of ideas.

**Figure 4**

**Methods of Analysis: making sense of and interpreting the data**



## **Constructivist Constant Comparison Analysis**

Below is a description of the underpinning analysis framework for this thesis. The analysis framework builds on the work of Reed (2007) developing a constant comparison technique as the framework of analysis for this thesis. Figure 4 illustrates how the framework for analysis has been integrated into the appreciative inquiry 4 ‘D’ cycle.

Making sense of the data using an appreciative inquiry methodology became an integral part of the data collection involving the participants and reference group examining the constructed analysis to provide rigour to the data collection at each stage of the 4 ‘D’ cycle (Koch 1994; Coffey and Atkinson 1996). Chapters 6 and 7 describe the analysis process in this thesis at each stage of the 4 ‘D’ cycle, discovery, dream, design and destiny. The analysis framework has been developed from the constructivist constant comparison analysis approach described below.

A constructivist approach places priority on the phenomenon of the study and sees both the data and the analysis as created from shared experiences and relationships with participants and other sources of data (Charmaz 2007). The constructivist grounded theorist take a reflexive view of their research processes and products. They consider how their theories evolve using reflection of both their own and their participants’ interpretation of meanings and actions. They assume that data and analyses are social constructions that reflect what their production entailed (Hall and Callery 2001). With this in mind analysis is contextually situated in time, place, culture and situation. Therefore seeing facts and values as linked researcher’s acknowledge that what they see and don’t see rests on values. Constructivism fosters the researchers’ reflexivity therefore

by becoming aware of presuppositions and how the research is affected by realising that preconceived ideas can be imported into the research whilst remaining unaware of starting assumptions (Charmaz 2007).

Appreciative inquiry uses an inductive approach to generate hypotheses but explains how participants build on their affirmative experiences, values and beliefs. An explanation of how grounded theory constant comparison analysis has been developed as a constant comparison technique to use with appreciative inquiry methodology is described in Chapter 6 and 7 of this thesis.

Appreciative inquiry does not tie the researcher to a rigid prescription of data collection and analysis. Similarly the grounded theory method depends on using constant comparative methods and researcher engagement (Charmaz 2007). This method sits well with the appreciative inquiry 4 ‘D’ cycle where participants and researcher are constantly making comparisons of data and findings. Comparative methods lend the study basic tools, the multiple interactions that occur in many forms at different levels to shape the content of the theory. Appreciative inquiry like grounded theory relies on the interaction of the participants in the research areas, developing between researcher and data, a period of reflection, the merging of ideas and then returning to the participants of the study to move the stories on. When using appreciative inquiry as a research methodology this occurs at each stage of the 4 ‘D’ cycle, the researcher interacts with and collects data from the participants, makes sense of the data, appraises and interprets the data and

returns to the participants with the construction of the analysis in preparation for the next stage of the cycle.

## **Constant Comparative Methods**

The ultimate goal of constant comparison method is to generate a theory or build a model that works, fits and is relevant (Guba and Lincoln 1989). The model is modifiable and not a validated fact (Strauss and Corbin 1990) in theory this lends itself to development with appreciative inquiry methods. Similarly to appreciative inquiry, grounded theory data are analysed concurrently with the data collection and the main issues are allowed to emerge during coding and conceptualising the data (Guba and Lincoln 1989; Strauss and Corbin 1990). The coding is divided into three stages, open coding to find the categories, axial coding to connect them and selective coding to establish the core category or categories (Strauss and Corbin 1998). Noting that the researcher's construction may be introduced for critique, this is highly subjective but does not violate the principles of constructivism so long as the participants have the opportunity to critique the researcher's formulations. In appreciative inquiry the participants and reference group have this opportunity at each stage of the 4 'D' cycle this also adds to the evaluation and rigour of the data collection. The researcher may well be the only person who has moved extensively between the participants, and therefore has the benefit of having heard the complete set of constructions. That particular construction is likely to be the most informed and sophisticated by the end of the process. This is not a position of evaluator power but merely a greater ability to facilitate and negotiate the process (Guba and Lincoln 1989).

Open coding is open and moves throughout the process to become selective. Theoretical possibilities are considered from the data with the open coding moving towards definitions or core conceptual categories. During open coding four questions are asked:

1. What is the data a study of?
2. What does the data suggest?
3. From whose point of view?
4. What theoretical category does this specific datum indicate?

(Charmaz 2007)

Open coding remains close to the data with an importance of keeping coding open to ‘spark’ thinking and allow for new ideas to emerge (Charmaz 2007). Open codes are provisional, comparative and grounded in the data and remain open to further analytic possibilities. The size of the unit of the data is a consideration into how to develop the process of initial coding. Line-by-line coding is for many grounded theorist the first step to coding. This works particularly well with detailed data about processes for example in interviews, group discussions and observations. Line by line coding prompts openness to the data and the ability to identify nuances in it. It can help identify implicit concerns as well as explicit statements assisting with the refocusing of future interviews. Charmaz (2007) suggests the following strategies:

- Breaking the data into component parts or categories
- Defining the actions on which they rest
- Looking for tacit assumptions
- Explicating implicit actions and meanings

- Crystallising the significance of points
- Comparing the data with data
- Identifying gaps in the data

By using these strategies flexibly the codes can be developed into theoretical categories with definitions within the coding. The flexibility of the process also allows the researcher to return to previously coded interviews to see if events and experiences explain a later important process. If not the data can be collected in the next stage of the study or new participants sought to extend the data collection in that stage.

Axial or theoretical coding is about linking together the categories from the open ended coding. The codes are more directed, selective and conceptual. Glaser and Strauss the founders of grounded theory have now formed diverging views on the approach to take when axial coding (Glaser and Strauss 1967). They take a purist grounded view arguing that axial codes and the form that they take should emerge from the data rather than be forced into a pre-determined format. Strauss and Corbin (1998) however work within an interactionist paradigm where the axial coding is viewed as leading to an understanding of the central phenomenon in the data of the context of the conditions that gave rise to the data, the action and interaction strategies by which it was dealt with and their consequences. Robson (2002) explains that whichever line is taken axial coding is about putting the data in a way that has been split apart into categories by open coding.

In the third (stage selective coding) one aspect of the core coding is selected and focused upon. This arises from the axial coding which gives a perspective on the relationship

between the related categories, giving a feel of what the study is about in a way that can be understood and explained. In grounded theory there must be a central integrating focus to the aspects that remain in the study. If more than one remains the notion is that they are into a single one, grounded in the data but is abstract, integrated and highly condensed. Strauss and Corbin (1998) suggest approaching this process from the ‘story line’, starting with a description of what the axial coding has produced moving into a descriptive account to a conceptualisation of the story line.

## **Questions of Rigour**

In establishing trustworthiness and rigour to this thesis Koch’s (1994) framework provides a decision trail that is based on credibility, transferability and dependability. Credibility is described in this thesis within the use of reflexivity beginning in chapter 1. Reflexive accounts of each stage of the 4 ‘D’ cycle are included in the construction of the analysis in chapters 6, 7 and 8 from my reflective diary and memos collected though the period of data collection. Credibility is further established within the 4 ‘D’ cycle (discovery, dream, design and destiny). At each stage of the 4 ‘D’ cycle the participants and members of the reference group were invited to read and comment on the construction derived from the analysis. Transferability is described in chapters 7 and 8 in relation to Admiral Nurse practice and making the choice to care. Dependability relies on the ‘audit trail’ of the thesis (Koch 1999). A theoretical journal and field notes were maintained throughout the year of data collection. The theoretical journal was updated at each stage of the 4 ‘D’ cycle using the constructions derived from the data and comments retuned by the participants and reference group. The field notes were written by a

volunteer participant at each stage of data collection. A memo was written to reflect on each stage of the data collection and used with the field notes and construction of the analysis to begin the next stage of the 4 ‘D’ cycle. Ethical and participatory considerations were noted and prompted adaptation to the multiple methods of data collection for example, to nominal group technique p.198. My reflexive diary and memos made poignant entries regarding the sensitive and distressing nature of the stories that were being told. I recorded how my professional nurse status and researcher intertwined into a participatory reciprocal experience. I sought the views of two experienced Admiral Nurses and my supervision team to support my reflections on these feelings and the construction of the analysis. The overall aim of this study is to provide a constructed reality of carers’ roles and the meaning of family-centred approach to the practice of the Admiral Nurse. Through reflexive accounts I bring my own pre-understandings and prejudices to the constructions. I have included my reflections of the journey of this study in the text of this thesis in chapters 5, 6, 7 and 8.

## **Summary**

This chapter has given the reader an insight into the philosophy of Paulo Freire and how his work influenced the development of action research and my choice of using appreciative inquiry as a research methodology for this thesis. The background and the way appreciative inquiry works as a research methodology has been described. A rational for using each method and a brief description of the methods of data collection (questionnaire, interviews, focus groups, photography and narrative, mind maps and nominal group technique) have been discussed. An overview of constructivist constant

comparison analysis has been given which has been adapted to use with appreciative inquiry in the following chapters. In Chapter 5, I set out the study design leading the reader through the development of my research journey to make choices about research methods that were inclusive and participatory to the wide range of participants who volunteered to be part of this study.

## **Chapter 5**

### **Study Methods**

In Chapter 4 I described the process of developing a methodology and constant comparison analysis technique for this thesis. The account in this chapter is a reflection of the development of the research journey I have taken. The process of ethical approval, sampling and consent are discussed and I further develop Koch's (1994) framework to establish the rigour and trustworthiness of the research.

Gaining ethical approval for this study was a lengthy but necessary process as the inclusion of carers and people with dementia brought ethical dilemmas and considerations to the progress of this thesis. I did not wish to unduly contact or distress carers and people with dementia due to their vulnerability. Professionals can feel burdened and their practice threatened when invited to participate in research. These were critical considerations when planning the ethical, sampling and consent process for this thesis. A reference group was therefore set up to support the study during the first stage of ethical approval. Alongside the process of ethical approval sampling was given consideration with the support of a reference group and the co-ordinator of *for dementia*. The process of consent was not undertaken until full ethical approval had been gained and I had made informal contact with individual carers and facilitators of the carer and people with dementia groups, Admiral Nurses and stakeholders. The importance of these considerations became evident as the data collection began. My reflections of the experience of the telling and listening to the stories told during the data collection are described in chapters 6 and 7.

Throughout the chapter I draw on the research text that influenced the methodological decisions to choose the research methods that make up the design of this inquiry: questionnaires, telephone interviews, photographs, narratives and focus groups. The constructive comparison technique is described in this chapter to contextualise the methods of analysis with the research methods.

To conclude the chapter the preliminary stage to the 4 ‘D’ cycle is described. A questionnaire was sent out to all 54 Admiral Nurses. The aim of the questionnaire was to gain a base line of the understanding of how Admiral Nurses are valued and to place their practice in context to the appreciative inquiry methodology. I was also very aware that as a practising Admiral Nurse I could be prone to making judgements and assumptions about the context of Admiral Nurse practice. An analysis is made of the data collected from the questionnaires to construct the context of Admiral Nurse practice.

### **Ethical Approval**

It has been argued for some time that all research can be potentially harmful to both the participant and researcher (Long and Johnson 2007). It is maybe more obvious to think that controlled trials involving invasive procedures or drug trails could unintentionally cause harm. However qualitative studies gathering data about sensitive topics can cause inadvertent emotional stress and potential damage to individuals. The ethical considerations about who the research is going to benefit, and deciding on the topic to be researched were all important considerations when developing the design and process of

this study. Individual ethical issues that arose throughout the study are reflected upon at each stage of the 4 ‘D’ cycle in this chapter and those following (Koch 1994).

Potentially there are several groups and organisations that can benefit from the outcomes and findings of the research. When action research techniques are used participants have the opportunity to be a co-researcher developing unknown or previously under developed skills. There are also potential benefits to the participants of this study by identifying and defining family values, skills and feelings of well-being pertaining to the role of caring for a person with dementia.

In addition to seeking and gaining ethical approval from Northumbria University (appendix 1) it was necessary to seek approval from the National Research Ethics Service. This approval was a priority as the research study extended to a nationwide service but it proved to be lengthy and at times frustrating. At this point the recruiting of participants to the study was at a very early stage. Members of the National Research Ethics Service committee required further clarification about the recruitment and support of people with dementia. This was based on the premise of people with dementia being vulnerable people who require protection; therefore an invitation to participate in the study should be considered by the person’s medical practitioner. To be able to do this the person requires information about the study, with an appropriate amount of time to make the decision, and, an approach that enables the person to decline or agree to take part. Changes were made to the information sheet and a medical practitioner’s letter drafted to

meet these requirements. National Research Ethical Committee approval was granted in April 2007 (appendix 1).

The second stage of the approval process necessitated approval from Research and Development Departments. In 2005 the second edition of the Health and Social Care Research Governance document was published (DH 2005). This document reflects the changes made to legislation in human tissue and mental capacity with provision to protect those who participate in research. Researchers must ensure they safe guard the rights, safety and well-being of participants. In addition data protection, ethics committees, informed consent and confidentiality were integral to the research process and are discussed in turn within this thesis.

The approvals were not without difficulties and proved to be a lengthy and bureaucratic process, with each Research and Development requiring different information and evidence on how the research study was to progress. This form of approval may not have been necessary in every Research and Development area following National Research Ethical Committee approval, as data were not collected within the boundaries of many of the Research and Development areas. Even though the approval may not have been necessary it is good practice when approaching a range of participants to take part in a research study. Full Research and Development approval was received in October 2007 (appendix 2).

The third stage of approval was to gain written consent from each of the service managers of the Admiral Nurse teams. This was requested via email to save time and was responded to positively and promptly. All the Admiral Nurse Service Managers consented to their Admiral Nurses' participating.

## **The Reference Group**

Considering the development of a reference group was important to the support of the study. Consideration was given to the range of potential participants in the study and what sort of advice and direction I would potentially require for its duration. Uniting Carers *for dementia* is an organisation set up by *for dementia* for carers who have received a service from an Admiral Nurse. The members of Uniting Carers *for dementia* are invited to participate in a range of activities and events in dementia care. Some members had an expressed interest in being part of research. A sample of these carers was approached by the co-ordinator of Uniting Carers *for dementia* to discuss involvement in the study. Consideration was given to the stage of their caring role and geographic distance to the London based *for dementia*. Easy access to London was important as meetings of the group were potentially going to be a requirement of participation. The carers who volunteered were a diverse representation of cultures, backgrounds and caring experiences (see p. 126 table 5 for more information). Those who had expressed an interest were contacted by telephone by me for an informal interview. Before I contacted each carer I sent out a personal letter with the information sheet and guidelines to being a reference group member (appendix 5). Nine carers and two Admiral Nurses became part of the reference group.

## **Sampling**

### a) Sampling for strand 1

The Admiral Nurses (n=54) were contacted by *for dementia* following a presentation by the researcher about the study to all the Admiral Nurses at their Practice Development Day earlier in the year. A participant information sheet was sent out to each nurse who expressed an interest in participating in the study (n=49) (appendix 5).

Following an initial presentation of an outline of the study to a group of carers from Uniting Carers *for dementia* the co-ordinator of Uniting Carers *for dementia* under took the preliminary enquiries to recruit the sample for strand 1. Carers were contacted by the co-ordinator of Uniting Carers *for dementia* to check their interest in becoming a participant and availability to participate. A personal letter, guidelines for the discovery stage and the study information sheet was sent out to each carer (appendices 5 and 6). An informal telephone interview was conducted with each carer firstly to introduce myself to the carer, secondly to check that they understood participation in the study. A protocol was used for each carer to ensure there was equity of information given to each person. Ten carers expressed interest in an informal interview, two decided not to participate at this stage, one due to personal reasons and one preferred not to give a reason. One later contacted me to ask if she could participate in the dream stage of the study, this was possible as the ethical approval allowed for participants to step on and off the study as they felt comfortable with (Manley *et. al.* 2005).

### b) Sampling for strand 2

The Admiral Nurse sampling was as for strand 1. Stakeholders from each of the Admiral Nurse Service Areas and *for dementia* were invited to the Admiral Nurse forum in March 2008, a total of 18 stakeholders were recruited to participate in the discovery stage, strand 2. Due to the geographical spread of this group they were invited to participate in dream stage, strand 2 via email or telephone interview. Five participants engaged through email in the design stage strand 2.

Carers and people with dementia were sampled from Admiral Nurse facilitated groups in two geographical locations in Kent, South East England. The sample was deliberately tied to the area through the ethical approval process and my ability to meet the groups in a location that was accessible. Two groups were chosen to include a diversity of people from different cultures, genders, caring and personal experiences in dementia care. A total of 20 carer's and 6 people with dementia participated in focus group 1 and 2. Prior to attending the group to collect data I attended to meet the members of the group to introduce myself and the research study. In one of the groups there was time to schedule a warm up exercise. Each member of the participating group was asked to pick a card from a selection (taken from greetings cards and similar publications) and asked to talk about what they liked about the picture and then what prompted them to choose it. A lively discussion took place with participants talking about their chosen picture. One lady chose a picture of snow drops because she had snow drops in her wedding bouquet. She and her husband who has dementia were then able to talk about their wedding day. When I returned to collect data for the study the group members remembered the previous exercise and were keen to engage in data collection. I wasn't able to introduce myself to

the other group in the same way due to previously arranged schedules for the group. This did not detract from the enthusiasm of the participants in the data collection but made the start slower as introductions were lengthier and felt very formal due to the necessity of going through the formalities of the research study.

## **Consent**

Free and informed consent is central to requirements of ethical research involving human participants. Informed consent first became a requirement after the second world war with the introduction of the Nuremberg Code in 1947 (Slaughter *et. al.* 2007).

Carrying out research with vulnerable groups of people has potential ethical dilemmas. The issue is whether a vulnerable person, in this case a person with dementia can rationally, knowingly and freely give consent (Robson 2002; Alzheimer's Association 2004). The dilemma of whether a person is able to give informed consent and at what stage of their dementia this is not possible is debated in the study by Buckles *et. al.* (2003). They found that people with mild dementia understood consent information for the study's minimal risk protocol risk. A third of people with moderate dementia demonstrated poor understanding; however the item addressing the participant's option to end participation was answered correctly. Reinforcement of consent information improved understanding in the participants with mild dementia. Understanding of research information is not a basis to gain consent and the assessment of decisional capacity in people with dementia individuals lack uniformity and is also highlighted as an issue in this study (Buckles *et. al.* 2003).

Pucci *et. al.*(2001) and Guerrero and Heller (2003) consider the role of the caregiver as a surrogate for the person with dementia and raise the question of education, culture and language of a person without a diagnosis of dementia and therefore the ability to understand the consent process. In recent years the role of the ethical committees in safe guarding the rights of the individual and the interests of society has been encouraged. The Alzheimer's Association (2004) has detailed recommendations for such committees. Assuming people with dementia are unable to participate in research reinforces negative stereo types of incapacity. This denies them the capacity to make meaningful contributions to research and share the benefits. It is morally unacceptable not to include people with dementia in research and significant limitations to dementia research would severely hamper effective treatments and interventions (Slaughter *et. al.* 2007).

To be able to address the tensions of these debates when gaining informed written consent for this study the process was broken down with each group of people who were being invited to participate. Within the realms of this study there was not the capacity to check each person's educational and cultural background and this information was not pertinent to the research question.

The written consent process began after stage 3 of the ethical approval process. Large print or electronic copies of the research study information sheet and consent form were made available, there was also a provision made for access to translated copies in an appropriate language.

## **The Process of Gaining Consent**

### *Reference Group*

Written consent was obtained from members of the research reference group after an informal telephone conversation. This was followed up by written information about the study and guidelines for reference group members about what participating would involve. The signed consent forms were returned to me by post, signed by me and a copy returned to each member of the reference group. Support and additional information to each person was available from me and the co-ordinator of Uniting Carers *for dementia*.

### *Admiral Nurses*

For the preliminary stage Admiral Nurses completing the questionnaire consented by completing it. Written consent was formally required for participation in strands 1 and 2. Each Admiral Nurse was sent a consent form with an information sheet and asked to consider participation. I was available to answer questions or give further information should it be required. Many of the participants attended groups without their consent form either previously completed, returned or with them. Asking for consent forms to be completed at the start of the groups was a tension for me and was highlighted in anonymous feedback from one participant. It felt difficult asking for written consent when everyone was sitting in close proximity, and I was unsure if the choice to participate was open enough (Pucci *et. al.* 2001). However one person did choose to leave in one of the groups, they later participated in strand 2.

### ***People with dementia***

For people with dementia consent was renegotiated at the beginning of each contact to ensure they were participating in a voluntary capacity and were able to remember the context of their participation (Buckles *et. al.* 2003). The groups of people with dementia were small, so having a conversation with each person was easier. I felt confident that each person who signed consent had capacity to do so. A letter to each person's General Practitioner was sent in accordance with the ethical approval. Some chose to take it to their surgery themselves, some preferred it to be posted. Two people who attended the groups did not sign a consent form. In conversation with their primary carer I felt it would not be right for them to do so. However, they were part of the group so they joined in. In strand one by listening and being acknowledged by members of the group, and, in strand 2 by helping to stick 'the values' under each heading. One person then helped with putting the furniture back after the group and thanked me for an enjoyable morning. Facilitating the group in this way it felt calm and inclusive although the formalities of ethics were clearly met (Slaughter *et. al.* 2007).

### ***Carers***

All the participating carers had received an information sheet and consent forms either at my informal visit or via the Admiral Nurse who facilitated their group. Most arrived either with their form complete or had handed it in at the previous meeting. I checked that everyone had signed a consent form and answered any questions. For example one lady was not sure what *for dementia* was, this was due to the interpretation of the wording. She chose to participate and completed her consent form. This process was repeated in the dream and design stage with strand 2 participants.

## ***Stakeholders***

Stakeholders were sent information about the study prior to the groups. Some participants had received it as part of the Research and Development approval and/or service manager consent. The same information was available for all participants on the day of the groups with a consent form. Verbal checks were made that each person had given written consent before the start of discovery stage, dream stage and design stage, strand 2. Only participants in discovery stage strand 2 were invited to participate in the dream stage and design stage strand 2 to ensure that they had received the correct information and had consented to participate.

## **Analytic Methods**

The analysis of data is the process of making ‘sense’ of the ‘raw’ data so that it can be summarised and communicated (Huberman 1994). Therefore, making sense of the information is a process of examining and organising it so that it can be discussed by others (Reed 2007). The framework for analysis for this thesis intertwines with the research methodology appreciative inquiry and constant comparative analysis (Charmaz 2007) developing a constant comparison technique to use with appreciative inquiry. Data were analysed by reading and re-reading transcribed text using constant comparison throughout the process of data collection and during the writing up period. The coding process was supported by the software package Nvivo7, though this was a more convenient data storage package than for analysis (see preliminary stage in chapter 6 for more information).

The introduction of computer software has been a recent development in qualitative research. The best known programmes are known as code and retrieve systems, which mean that they allow the researcher to code text using the software and then retrieve the coded text. Being a novice to data analysis Nvivo 7 was chosen as training and support was available at Northumbria University. The use of Nvivo7 meant that the hands on tasks associated with the interpretation process were completed on the computer and the software used as a data base and retrieval system for the data in strands 1 and 2.

Traditional methods were mixed with the use of Nvivo 7 with an initial reading through of the transcripts to get an overall ‘feeling’ for the data collected (description coding). The software was then used to go through each set of data marking sequences and themes of text in terms of codes. Each code was collated into themes or ‘nodes’ to store chunks of text related to each code. This way of coding replaced the traditional way of physically writing in margins, making photo copies of transcripts, filing notes and reflections, cutting out chunks of text and storing them together. Nvivo 7 does this automatically providing a neat and easily accessible data base for data. However it is important to retain an awareness of the data as fragmentation can result in de-contextualising the data (Buston1997; Fielding and Lee 1998). A sensitive awareness of the data was maintained throughout the study by returning to the participants in each stage of the research with the interpreted data. This is supported by Bryman and Burgess (1994) who note that computer assisted qualitative data analysis enhances the transparency of the process of coding data adding to the validation and rigour of the thesis. It also obviously provides a fast and efficient way of coding and retrieval which helped with the time constraints of completing the study.

## **Linking Qualitative with Quantitative Data ‘Getting a feel for the data’**

The data from the questionnaire in the preliminary stage gave a broad overview of the nature of Admiral Nurse practice. Some quantitative data were collected about length of service and level of qualifications alongside some initial data about how the Admiral Nurses saw their current role (see preliminary stage chapter 6 for more information).

Experiences by Rossman and Wilson (1984; 1991) cited in Miles and Huberman (1994) p. 41 suggest that qualitative data and quantitative data can be linked and suggest three broad reasons: a) to enable confirmation and corroboration of each other via triangulation; b) to elaborate or develop analysis, providing richer detail; and c) to initiate new lines of thinking through attention to surprises or paradoxes. The small amount of quantitative data from the questionnaire provided background information (c) to the study supporting the development of the data collection in the discovery stage strand 1 and 2.

The level of coding used in the preliminary stage was descriptive coding. This level of coding requires only a small amount of interpretation identifying phenomena in pieces of text. The same segment of text could have been interpreted more fully but there would have been a danger of bias at this early stage of data collection.

## **Interpreting the Data**

Memoing was used as a constant, unrestricted process that began when first coding providing an approach to finding relationships enabling the analyst to reach levels of abstraction and ideation with an aim of developing theoretical ideas (codes). It is a pivotal intermediate step between data collection and writing enabling the analyst to generate ideas as they occur (Glaser 1978). In this thesis a constant comparison technique was used to underpin the appreciative inquiry 4 ‘D’ cycle. Each phase of the 4 ‘D’ cycle

is interpreted searching for textual evidence to craft the questions of the next stage (Cooperrider, Whitney and Stavros 2005).

## **The Interpretative Process**

The interpretative process is discussed in relation to the appreciative inquiry 4 ‘D’ cycle. It is combined with the interaction of data to explore what is said. This underpins the development of ‘the stories’ told and ‘my theory’ with the use of constant comparative analysis at each stage, based on relevance of theoretical sampling and theoretical sensitivity (Charmaz 2007). In line with the over arching framework of appreciative inquiry, understanding developed from a naïve to a critical in depth interpretation. As a way of shaping the inquiry, multiple purposeful readings were taken from different reader positions to illuminate different aspects of the data (example appendix 9). The narrative component of the discovery stage centred on the development of carers’ values, principles and feelings. During the discovery stage thoughts and meanings within the text were uncovered and variables identified, labelled categorised and related together.

In the design stage axial coding was used to explore relationships between codes and the data put together in a new way to aid understanding and new learning. Finally in the destiny stage constant comparison between the newly identified relationships, values and principles led to the identification of four carer relationships and four Admiral Nurse principles both underpinned by a set of values. As the data collection progressed emerging themes were fed back to the participants at each phase of the 4 ‘D’ cycle using appropriate language (Killick and Allen 2001) and with their agreement these were integrated into the next stage of the 4 ‘D’ cycle. To maximise rigour, coding of the data

was viewed at each stage by participants and members of the reference group (Koch 1994). This approach aimed to enhance awareness of emerging concepts and reduce bias.

### ***Open coding***

Analysis began during the preliminary stage by developing a naive interpretation of the literature. The qualitative text of the questionnaires was read through and the quantitative data separated for processing as background to the study. A reflection was written about the process of delivering the questionnaire and the qualitative text re-read to identify themes on the nature of Admiral Nurse Practice to provide a first level interpretation of the data. The discovery stage commenced with telephone interviews and focus groups using mind mapping. The questions were developed from the data collected in the questionnaire and literature on family-centred care. The telephone interviews were transcribed and read through and coded using Nvivo 7 (they are presented in depth in Chapter 6, example appendix 8). The mind maps from each focus group were transcribed along with the field notes and coded using Nvivo7 (examples appendix 10, 11 and 12). This developed a naïve interpretation of the data and moved the analysis into the dream stage of the appreciative inquiry 4 ‘D’ cycle. During this stage photography and narrative was used to further illustrate how carers perceived periods of well-being and value to their caring role (examples appendix 14). The second reading of the data identified individual stories unique to each participant. At the same time the data from the mind mapping in the focus groups identified similar themes across all the groups when investigating the value of the Admiral Nurse.

### **Axial Coding**

It is well known that codes will change and flourish as the data collection period continues. The appreciative inquiry ‘4D’ cycle supports this development in a participatory way giving an opportunity for each stage of the analysis to be validated by the participants. There is always more going on than an initial coding frame can develop and some analysts have names for coding procedures later in the research cycle. For example, Lincoln and Guba (1985) discuss these: 1) ‘Filling in’: adding codes reconstructing a coherent scheme as new insights emerge and new ways of looking at the data set emerge. 2) ‘Extension’: returning to materials coded earlier and interrogating them in a new way, with a new theme, construct or relationship. 3) ‘Bridging’: seeing new or previously not understood relationships within units of a given category. 4) ‘Surfacing’: identifying new categories.

My initial enthusiasm of using the Nvivo 7 package waned a little at this point; I found I was losing the ‘feel’ of the data. Reflecting on this now it may have been due to my lack of information technology experience with Nvivo 7. More probably it was the comfort of being able to handle the paper and reflect on what had been said and how it had been expressed, this ‘feel’ for the data appeared to become somewhat lost when using Nvivo7. I therefore continued the coding process by writing concepts and ideas into the margins and linking them manually with the themes and codes from the initial coding process (example appendix 8).

The dream phase of the data collection underpinned the development of the analysis exploring the relationships between the codes and putting the data together in new ways to develop the understanding and learning phenomena. Relating categories and linking them with their characteristics and sub-categories is important for the emerging theory (Lincoln and Guba 1985). Relationships and links are connected ‘what, when, why and how’ and the consequences of the ‘event’ (Strauss and Corbin 1998). Strauss and Corbin call this type of categorising axial coding.

### *A Constant Comparison Technique*

A constant comparison technique was used in the design stage of the appreciative inquiry 4 ‘D’ cycle. The process of analysis continued into the destiny stage of the appreciative inquiry 4 ‘D’ cycle focusing on the reflection of telling of the stories and identifying the connections and patterns between them. This process led to a re-examination of the data and the parts of the analysis that had been undertaken throughout the 4 ‘D’ cycle. The separate elements were drawn together in a way that allowed for social meaning of this complex social situation and Admiral Nurse practice. Through the synthesis of the participants’ stories, and understandings the destiny phase of the interpretative process opened up the possibility, for a new generation of stories of carer relationships and how Admiral Nurse practice can support this. The constructs developed were major categories formulated by the participants and the supporting literature. This approach aimed to enhance awareness of emerging concepts and reduce bias.

An integral part of appreciative inquiry in the destiny stage is for the participants to develop provocative propositions. Traditionally this is done as part of the researcher’s

data analysis using memos and field notes with the coded data (Miles and Huberman 1994). Provocative propositions were crafted from coded data, memos and reflective narratives in the design stage of the 4 'D' cycle. Kell, (1990) approached the development of provocative positions in a similar way during a multi-case study of the effects of the use of computers in a classroom environment. In this study the propositions took the form of emerging hypothesis of the data. An example of a proposition from this study is:

*'Individualised learning and self-directions, as well as cooperation and peer teaching, are promoted through computer use, and some transfer of these learning styles to other class activities may occur'*

(Kell 1990 in Miles and Huberman 1994 p. 75.)

The provocative propositions were again revisited at case analysis meetings with supervisory colleagues and at focus groups 3. Questions asked were: 1) what are the main themes and impressions, what is going on? 2) What are the explanations, speculations, and hypothesis? 3) What could the alternative interpretations, explanations and/or disagreements be? (Adapted from Miles and Huberman1994).

## **Managing the Data**

All the field notes, transcripts, photographs with narratives were stored in computer files that were securely protected. Prints of photographs were stored in a secure locked environment along with the mind maps. The interview transcripts and focus groups were coded with a letter and number that correlated with the same participant or group through each stage and strand of the study. Participants were asked how they would like to be addressed in the thesis and chose to keep their original code e.g. A1 with letters to mentioned family members, friends and professionals. The assignment of codes

anonymised the data in a way that provided ease of access to individual files and whole data sets for each stage of the study. Each data set was generated within a particular context e.g. ‘carers research study group’ ensuring data from each stage of the study was easily retrievable.

## **Summary**

In this chapter the process of seeking ethical approval has been discussed as it raised the ethical dilemma of the inclusion of vulnerable adults. The process of ethical approval, sampling and gaining consent therefore required support from a reference group and was a lengthy process. The framework for analysis was discussed signposting the reader to examples of application and development of a constant comparison technique in chapters 6, 7 and 8 of this thesis.

In Chapter 6 the journey of data collection begins. Firstly the preliminary stage is described to contextualise Admiral Nurse practice. Comparisons are made in the analysis stage with the background and context of dementia in chapters 1 and 2 and the family-centred literature in chapter 3. The chapter is divided into sections to lead the reader through the first three stages of the 4 ‘D’ cycle, discovery, dream and design. Each stage of the cycle is described in chronological order (in reality the data collection overlapped), with the analysis actively developing and evolving throughout each stage of the 4 ‘D’ cycle.

## **Chapter 6**

### **Discovery, dream and design**

The previous chapters in this thesis have set the context for the remainder of this research journey. The discussions set the context for the study as applied to my own personal experience, practice reflection and experiences and passion to strive for recognition of personhood for people with dementia and their carers. In Chapter 2, I described the context of dementia care from a bio-medical, psycho-social and relational point of view and gave an overview of some of the dementia literature that pertains to this thesis. The background to the literature was further developed in Chapter 3 to discuss the strengths and weaknesses of a family-centred approach to nursing and how it has tenuously been applied to mental health. Chapters 4 and 5 gave the methodological base for the study, appreciative inquiry, and described the study methods. The process of writing the background to the study chapter 1, the contextual chapter 2 and the literature review discussing family-centred approach chapter 3 began the process of making sense of previous knowledge, research and Admiral Nurse current practice.

In this chapter the information and data from the preliminary stage have provided texture and context to inform the beginning of the 4 ‘D’ cycle (discovery, dream, design and destiny) and give an insight into the participatory nature of the study. I was however aware at this early stage that ‘problems’ required sensitive listening and empathy to allow the ‘best of’ and value to emerge (Reed 2007). I had confirmed this by using an

appreciative inquiry approach within my practice as a senior lecturer delivering a team building programme with a group of care workers.

A questionnaire (n=54) was used to construct the context of Admiral Nurse practice. A total of 27 questionnaires were received for analysis. The data were analysed and comparisons made to information gathered for the background and context to this thesis (chapters 1 and 2) and family-centred literature in chapter 3 in conjunction with the data from the questionnaire. The emerging theory was then overviewed by the reference group before being used to develop the discovery stage of the 4 'D' cycle.

Following the preliminary stage data collection was completed in two strands that crossed each of the stages in the 4 'D' cycle (table 4). Firstly in the discovery stage with a group of carers and secondly with groups representing: carers; people with dementia; Admiral Nurses and stakeholders. During the discovery stage 8 carers completed an audio recorded telephone interview supported by field notes and reflective notes. Planned recorded telephone interviews were conducted across a 10 day period in November 2007 for duration of 25 to 45 minutes. Alongside the data collection with the 8 carers, a series of 11 focus groups (93 participants) were held to include voluntary participation of: carers; people with dementia; Admiral Nurses and stakeholders. Each group undertook a mind mapping approach to the recording of the focus group, supported by a note taker and reflective notes. The dream stage spanned a period of 8 months. The carers group was joined by another carer, giving a total of 9 participants. The carers were given a disposable camera with 27 prints and guidelines to capture the value or 'best' of within a

caring role. The camera was returned for developing and the photographs sent back to the carers. Each carer was asked to choose 6 photographs and write a narrative to describe the ‘best’ of or value of their caring role. Alongside of this, focus groups were facilitated to further examine the value of the Admiral Nurse. A total of 8 groups were facilitated (60 participants) and a further 4 stakeholders contributed via email (see table 4 for an overview of the data collection).

Finally, in this chapter the 4 ‘D’ cycle develops into the design stage. This stage involves participants in working through the process of designing future services, based on the ‘best of’ practice that they have discovered and the dreams they have had where they have imagined ideal practice. A focus group for each consecutive part of the study was facilitated to gain an overview of the data collected and co-constructed through the previous stages of the 4 ‘D’ cycle and to discuss in the destiny stage the provocative propositions that began the construction of the final findings discussed in Chapters 7 and 8.

**Table 1****Overview of data collection**

<b>Method of data collection</b>	<b>Date</b>	<b>Appreciative Inquiry Stage</b>	<b>Number of Participants</b>	<b>Participants</b>
Questionnaire	04/09/07 – 28/09/07	Preliminary stage	54	Admiral Nurses
Telephone Interviews	26/11/07 – 30/11/07	Discovery (strand 1)	8	Carers
Focus Groups (mind mapping)	07/01/08 – 31/03/08	Discovery (strand 2)	11 groups 93 participants	Carers, people with dementia, Admiral Nurses and stakeholders
Focus Groups (adapted nominal group technique)	31/03/08 – 23/05/08	Dream (strand 2)	8 groups 60 participants	Carers, people with dementia and stakeholders
Photography and narrative	18/02/08 – 26/05/08	Dream (strand 1)	9	Carers
Focus Group	25/06/08	Design	1 group 7 participants	Carers
Focus Group	11/09/08	Design	1 group 4 participants	Carer, Admiral Nurses and stakeholder

## **Preliminary stage: Constructing the context of Admiral Nurse Practice**

In October 2007 a questionnaire to construct the context of Admiral Nurse practice was sent out as a postal questionnaire to 54 Admiral Nurses. After being screened for identifying marks and text by an administrator at *for dementia* the questionnaires were returned to me for data interpretation. A four week return had been requested that was unfortunately disrupted by a national postal strike. A total of 27 questionnaires were returned following an extension of two weeks for the return date to allow for the disruption of the postal strike (Edwards *et. al.* 2002).

In order to develop the inquiry and draw out the ‘stories’ or data questions needed to be asked and topics chosen to focus the research. The findings then became the ‘vision for the future’ or data to feed in to the discovery stage of the 4 ‘D’ cycle (Cooperrider *et. al.* 2005). To develop the research questions it was necessary to gather data from the Admiral Nurses about their current practice, carers about their value of their caring role and gain a perspective of how carers, Admiral Nurses and stakeholders viewed the value of Admiral Nurse Practice.

## **The questionnaire**

Careful consideration was made in choice of method and the design of the questionnaire. As time was restricted a pilot was not run but the questionnaire was sent for comments to members of the reference group. Slight amendments were made to the wording and layout following consultation.

The aim of the questionnaire was to gather evidence of the nature of Admiral Nurse practice. Each concept of the questionnaire represented a selection of different elements of Admiral Nurse practice drawing on the common features. Copies were also available to download via email. 27 questionnaires were received back n= 27. This was lower than expected considering the preparation that had been completed prior to them being posted out. Some reduction could be accounted for because of the national postal strike but there were more sensitive considerations. There is a possibility that the Admiral Nurses felt that their practice was going to be judged in a detrimental way, the data would contribute to practice changes that they would not be involved in influencing, or that they felt that the research study was not an important part of their practice, that is there was no ownership to the study. It is noticeable from the data that there are a large percentage of Admiral Nurses with graduate skills; post registration education in dementia care and some other Higher Educational awards. A high number have significant practice experience although not only in a dementia care capacity (see table 1).

**Table 2    Admiral Nurse Qualifications**

Professional Qualifications	Academic Qualifications	Year of Qualifying	Service Title	Length of Service
RMN 27	BSc 12	1970-1980 4	Admiral Nurse 14	0-5 months 2
RMN/RGN 5	Specialist dementia care (ENB 911 or equivalent) 8	1980-1990 15	Team Leader 9	6-12 months 2
SEN 2	MSc/Ma 2	1990-2000 6	Senior Admiral Nurse 1	1-5 years 8
	PhD 1	2000-2005 2	Research Fellow 1	5-10 years 10
	PGC(HE) 1		Lead Practice Development 1	11+ years 1

**Table 3 The Value of Practice Development**

Attend clinical supervision	Benefits of clinical supervision	Attend Peer Group Supervision	Benefits of peer group supervision	Attend practice development	Work as part of a multi-disciplinary team
Yes 25	Extremely beneficial 16	Yes 25	Extremely beneficial 15	Yes 26	Yes 19
No 2 (not in clinical practice)	Beneficial 4	No 2 (not in clinical practice)	Beneficial 7	No 1 (only works one day a week)	No 8
	Quite beneficial 5		Quite beneficial 4		
	Not very beneficial 0		Not very beneficial 1		
	Not at all beneficial 0		Not at all beneficial 0		

An aspect of being an Admiral Nurse that is highly valued is the practice development that is available to each nurse; this is supported by *for dementia* in collaboration with the service host organisation. To obtain an overview of the usefulness and value to the Admiral Nurses a set of questions were developed the results are described in table 3. The Admiral Nurse Competency Framework appears to be being used as a practice development tool with few Admiral Nurses finding a real value in its completion. This could be due to the recent implementation of the Knowledge and Skills Framework within some host organisations or, there has not been a clarification about the use of portfolio development for registration as a specialist or advanced practitioner (Keady *et. al.* 2007b p. 305).

### **The value of the Admiral Nurse**

To be able to craft the questions to begin the 4 'D' cycle (discovery stage) the Admiral Nurses were asked how they felt carers valued their practice. The replies to this were subjective with the majority feeling well valued in their role,

*'The immense burden and emotional strain placed on carers and families can often feel overwhelming and hopeless, often leading to carer break down. The chance of being able to discuss their difficulties and feelings in confidence with a professional who is impartial and reassuring leads to an increase in the confidence and self esteem'*

*in the carer and better coping abilities. This I believe leads to a better quality of life for both carer and person with dementia'.*

(Questionnaire number 11)

and

*'I believe they value information sharing about dementia and other services, benefits etc, strategies for coping, opportunity to 'share' their story, support with accessing services, feeling supported, being advocated for, having their needs heard and being addressed (where possible), having their role acknowledged. The above is based on feedback received through evaluating action plans and comments received when moving on'.*

(Questionnaire number 21)

How Admiral Nurses currently work with families is usually dependant on the situation and clinical judgment taken at the time. Seven Admiral Nurse said they always worked with the family and 20 sometimes. There were a range of comments to this question showing flexibility in the how the Admiral Nurse works with a carer,

*'I frequently work with wider family but this is determined (usually) by the initial referee. Depends on many factors whether joint family meetings, or separate contacts (prefer first) but find it is often arbitrary deciding on a main carer when many family members involved and supporting the person with dementia and each other (sometimes not supporting each other). Especially in certain ethnic communities.'*

(Questionnaire number 7)

*'Whenever possible I work with the wider family and have often met with multiple family members. I will often work via phone and email with distanced family members who are unable to meet regularly but wish to know more about how to support primary caregivers.*

(Questionnaire number 23)

The comparison of the data included the background and literature in conjunction with the data from the questionnaire. I found using Nvivo7 quite time consuming and confusing with so many elements to choose from. Reminding myself that this was an initial comparison and not wishing to introduce a bias I decided instead to read the data through and then on a

second reading make line by line comments in the margin of the consolidated questionnaire data. Themes that emerged from this process are displayed in table 4. The reader will note that the emerging themes closely link with the themes raised in my reflexive account and the review of the family-centred literature Chapter 3.

**Table 4 Emerging Themes (preliminary stage)**

<i>Emerging themes Background knowledge and practice:</i>	<i>Emerging themes Empirical base:</i>	<i>Emerging themes Values of Admiral Nurse Practice:</i>
Family and carer relationships Nursing knowledge Nursing skills Partnerships Information Communication Health & social policy Education Practical advice Values and beliefs	Caring partnerships Education Information Collaborative Negotiation Shared beliefs Emotional support Physical support Empowerment Carer expertise Nursing Knowledge Listening Carer competence Nursing skills Values and beliefs	Practical information Emotional support Access to services Education Training Coping Strategies Signposting Honesty Trust Sharing Impartial Professional Advocate Relationships Flexibility Availability Reassuring

The following five points draw together the data analysis of the preliminary stage and were used to develop the questions in the discovery stage: empowerment (1); negotiation (2); facilitating (3); information (4) and partnerships (5).

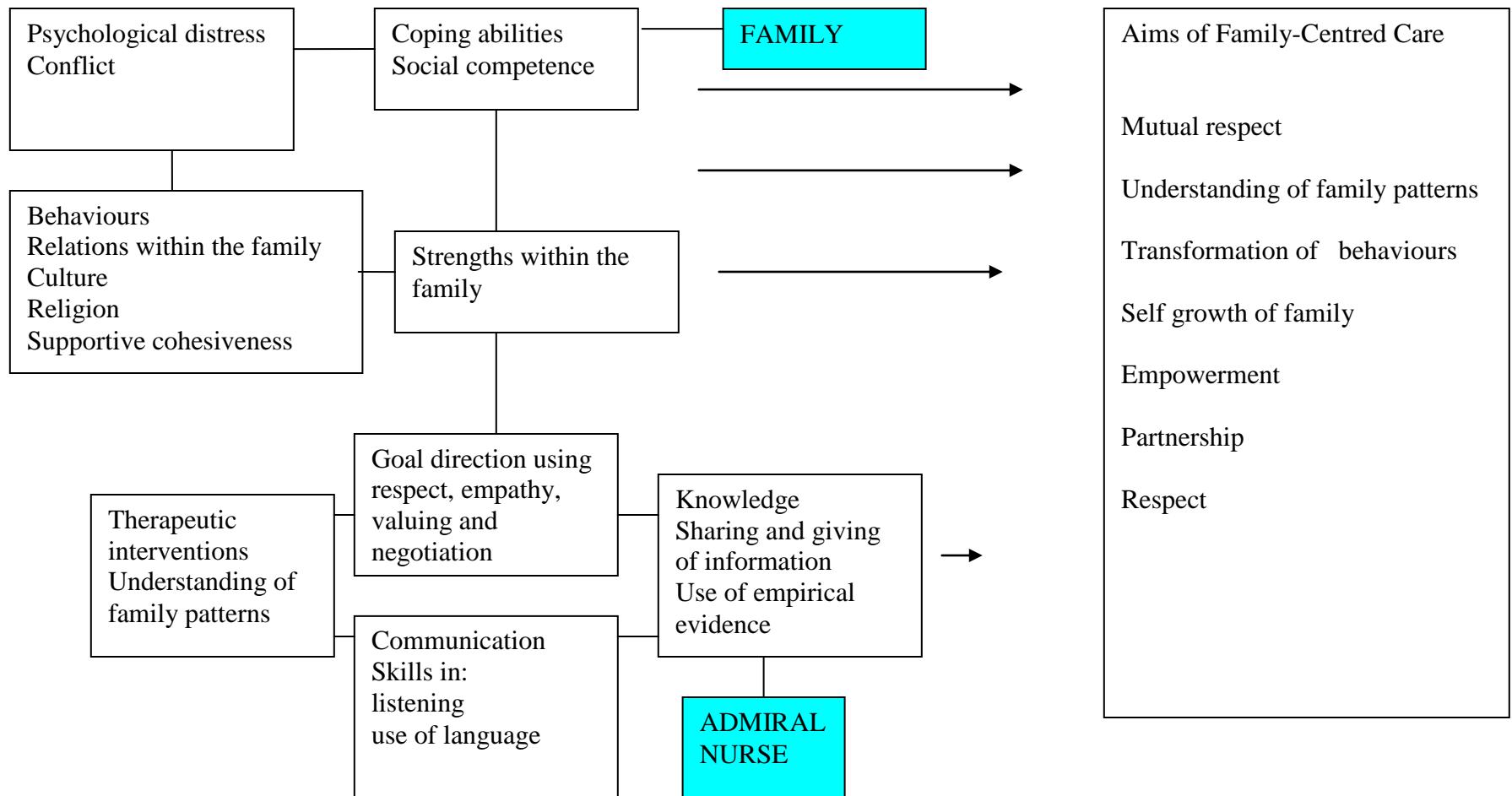
1. Empowerment (aims to psychologically give a sense of mastery and control to family, socially to empower a participatory competence).
2. Negotiation (structuring expectations, valuing family involvement).
3. Facilitating (communication skills - listening, silence, validating, acknowledgement of family skills and experiences).
4. Information giving (participatory experiences – physical, psychological, social).
5. Partnerships (relationships, decisions, collaborative practice, advocacy).

To begin the data collection within the 4 'D' cycle the data from the questionnaire required drawing together with the context of the literature discussed in Chapters 2 (contextual information) and Chapter 3 (a family-centred approach). To support the drawing together I kept a theoretical diary throughout the life of the research study which proved essential in crafting the questions for the beginning of the data collection (discovery stage) (see figures 5 and 6).

Drawing further on the work of Franck and Callery (2004) (theoretical diary 01/06/2006) the concept of a family-centred approach was further compared. The constructs of: respect; empowerment; negotiation; health care needs and partnerships are comparable to the questionnaire data about Admiral Nurse practice. These constructs fall within the concepts of support of family/person with dementia healthcare needs and the person with dementia/family service. The empirical indicators as identified by Franck and Callery (2004) are possibly carer abilities/competencies that could inform the sub concepts: physical needs; health promotion; decision making; information giving; collaborative working; communication skills; environmental/social care; advocacy; sharing; mental health needs; partnerships; coping strategies; cultural and religious health; responsibilities; therapeutic interventions and family behaviours.

Using these comparisons the interview questions were crafted from the emerging themes in dialogue with the supervision team and reference group (supervision session 19/10/2007) (figure 5). The appreciative inquiry questions were written to uncover the 'best of'. The title introduces the topic with a set of questions that explore the different aspects of the topic (figure 6).

**Figure 5** Relational Diagram to Represent Family-Centred Care



**Figure 6****Crafting the Questions for the Discovery Stage of the 4 'D' cycle**

<b>Emerging themes from the empirical base</b>	<b>Emerging themes from background knowledge and reflections of practice</b>	<b>Emerging themes from preliminary stage</b>			
Caring partnerships Information Negotiation Emotional support Empowerment nursing knowledge Carer competence Values and beliefs	education collaborative shared beliefs physical support carer expertise listening nursing skills	Family relationships Nursing skills Information Health & social policy Practical advice Professional relationships	nursing knowledge partnerships communication education values and beliefs	Practical information Access to services Training Signposting Trust Impartial Advocate Flexibility Reassuring	Emotional support Education Coping Strategies Honesty Sharing Professional Relationships Availability
Comparison of themes					
<b>Carers</b>		<b>Admiral Nursing</b>			
Family and carer relationships Skills Expertise Competence Negotiation	Support Knowledge Values and beliefs Information sharing Partnerships	Caring Nursing skills Information giving and sharing Empowerment Nursing knowledge Education	Relationships Negotiation  Social & health policy Partnerships Competence		
Crafting the questions		Crafting the questions			
<ul style="list-style-type: none"> <li>➤ Tell me about a time you felt things went/have been going well.</li> <li>➤ How did that make you feel?</li> <li>➤ Was there anything about the relationships with the people around you that made this go well?</li> </ul>		<ul style="list-style-type: none"> <li>➤ What is valued about the Admiral Nurse?</li> </ul>			
————— Reference Group —————					

## **6.1 Discovery - beginning the 4 'D' Cycle**

The task of the discovery stage is to appreciate the best of ‘what is’ and begin to develop the empirical understanding of this thesis. Traditionally in appreciative inquiry the discovery stage is a period to collect and share the ‘story’ of exceptional accomplishments and to explore the ‘life-giving factors of the organisation (Cooperrider *et. al.* 2005).

One of the key factors in using appreciative inquiry as a research methodology is the collaborative working with the literature and participants of the research. To be inclusive and collaborative an appreciative inquiry study must actively support and encourage participants, hearing their voices and allowing the expression of views. The importance of hearing different views from different knowledge base is highlighted by Reed (2007) and was an important factor in planning and conducting the discovery stage of the study.

### ***Telephone Interviews***

The telephone interviews capture the stories of 8 carers who recount their relationship experiences of caring for a person with dementia. They talk about the complex and emotional world of how they share their lives with the person they are caring for, their family members, friends and professionals. This is a world of stigma, burden and stress partially designed by the literature, media and the historical creators of hopelessness in dementia care (Iliffe *et. al.* (2005); Clare *et .al.* (2008); Garand *et.al.* (2009); DH 2009). Each carer is the main character in their story, playing many parts in the stories of others. They tell their story in a telephone interview about times when they have felt a sense of well-being and/or being able to use skills and knowledge they already had (Whitney and Trosten-Bloom 2003; Cooperrider *et. al.* 2005). Each story is unique, highlighting different emotions, some problematic and distressing and feelings of well-being and skill in a carer’s life. Remembering the complexities and the emotional journey each carer took, I re tell their story (Tugade and

Frederickson 2004). The data derived from the telephone interviews are presented as reconstructions of the stories told.

The telephone interviews were facilitated using an appreciative inquiry structure to explore what had gone well and the best of in a caring role. Guidelines were sent to each carer prior to the telephone interview to allow time for some reflection and exploration into their experience and expertise (appendix 9). Each telephone interview was audio recorded. Field notes were taken during the interview and a personal reflection of each experience was written after each interview.

### ***Pre-interview contact***

Following initial contact from the co-ordinator of Uniting Carers *for dementia*, each carer was contacted by telephone to discuss their participation in the research. The telephone conversation allowed for questions to be asked, concerns or issues to be voiced and for a provisional relationship to be built before the main interview. An overview of the details of each carer who participated in the study can be seen in table 5. Following the informal contact and the receiving of verbal consent to participate, each carer was sent a letter with a consent form and written information about the study with a pre paid envelope for return to me (appendix 5, 6 and 7). On receipt of the signed consent form it was checked and copied. One copy, signed by me, was returned to the carer and the other filed for the research records. At this stage one carer wrote to say she felt unable to participate in the telephone interviews as she was feeling vulnerable and unsure of her feelings. She was due to visit her family abroad and would contact me on her return. I contacted her by telephone to reassure her that she could join the study at a later stage should she wish and that I would keep her up to date with the progression of the data collection. The telephone interviews continued with 8 carers

participating. An appointment was made with each carer at an agreed time and date and confirmed in writing with a copy of the interview questions.

### ***The telephone interviews***

The questions asked in the telephone interview were designed to build on the findings from the questionnaire context of Admiral Nurse practice (Chapter 5), my reflections (Chapter 1) and the review of the dementia and family-centred literature drawing on the work of: Whitney and Trosten-Bloom (2003); Cooperrider *et. al.* (2005); Reed (2007).

Telephone interview questions:

- Tell me about a time you felt things went/have been going well?
- How did that make you feel?
- Was there anything about the relationship with the people around you that made this go well?

Each interview began by reminding the carer of my name and the purpose of the call and checking that it was a convenient time to talk to them. I reminded them that they had given written consent, participation was voluntary and that the call would be audio recorded.

**Table 5** An overview of carer details

(Definition of ethnicity as advised by the Office for National Statistics 2008 <http://www.ons.gov.uk>)

Carer	Age	Carer Ethnicity	Gender	Employment	Caring for	Type of dementia	Type of caring environment
A1	83	White British	male	retired	wife	Lewy body	Home/care home
A2	76	Other White Background	female	retired	husband	Alzheimer's disease	Home/care home
A3	50	White British	male	Works full time	father	Alzheimer's disease	Own home
A4	72	Other White Background	female	retired	mother	Alzheimer's disease	Home
A5	65	White British	female	retired	husband	Vascular dementia	Own home
A6	80	Other White Background	female	retired	husband	Pick's disease	Home/care home
A7	52	Other White Background	female	Works part time	mother	Alzheimer's disease/vascular	Own home/care home
A8	67	Black British	female	retired	husband	Alzheimer's disease	Home/care home
A9	58	Black British	female	Gave up work to care	mother	Alzheimer's disease	Home/care home

Not knowing the carer and their situation required sensitive and thoughtful interviewing as I was aware that after the call finished they would possibly be alone with memories and/or feelings that they had not thought about for a long time. I started the interview by asking some factual information. For some this was a repeat of details they had disclosed in our informal conversation but following the receipt of written consent I could now record this information. It was also important to put people at ease and discuss the same things with each carer. I was particularly aware of how emotionally difficult the interview may be after writing my own reflexive account for this thesis. The participating carers live across a wide geographical area of London and South East England. They each come from different ethnic and cultural backgrounds and have varying experience of caring for a person with dementia (see table 6 for more information). Some of the carers had prepared answers to the questions carefully, writing down their answers before I called. Each carer was aware that we were going to be talking about the ‘value’ and ‘best of’ their experience, this was received with surprise and feelings of uncertainty about whether it would be possible to talk about difficult times with a positive view. In fact, it was noticeable that to be able to recall a time of wellbeing each carer had to tell of a time of trauma and/or distress (Tugade and Frederickson 2004). Each carer had made adjustments to their relationships as they made their shared way through the journey of dementia. One of the major adjustments they made was the emotional journey of taking control of the relationship with the person with dementia. How they did this and how they managed the relationship is as individual as each of them. Some found practical ways of supporting the relationship, others valued the support of an Admiral Nurse to work with the emotional changes within their relationships, whilst some felt emotionally restricted until after the person with dementia had died and they were able to ‘give something back’. The changing emotions they experienced were not to be ignored; they included the trauma and burden of pre diagnosis, diagnosis, changing behaviour, changing and developing

relationships (Reed 2007). For each carer the attention then shifts to times when the carer felt a sense of wellbeing or when they felt things were going well. Presenting the data in this way shows the extreme emotional journey that each carer travelled to reach a sense of how they managed the many relationships they have other than the relationship with the person with dementia. Each carer had an individual and different experience at notably different times in the caring trajectory. This challenges the way that support and care of carers of people with dementia is traditionally given. For example it often assumed that carers only require transient support and information at point of diagnosis); or the relationship dies with the person with dementia and support is withdrawn on the death of the person with dementia.

Before making contact with the carers I gave each person a code to protect their identity, along with that of the person they are caring for/cared for and their family and friends. After transcribing the data each transcript was sent to the corresponding carer to be read and any wording or discrepancy taken out or adjusted, a pre paid envelope was supplied for their reply. For example one carer removed some personal details she felt were not relevant to the research. The carers were asked to choose how they would prefer to be referred to in the study either by code or a chosen name. All the carers decided to keep the existing codes which are letters or numbers. (Unfortunately this makes the reading of the data feel impersonal and does not fit with my original intentions of being able to keep the emotion of each participant alive for the reader). I refer to myself as P as the participants were all invited to call me Penny.

### *The Carer's Stories*

Each participant's story has been reconstructed from the transcribed text of each telephone interview. The reconstructed stories were themed by hand, line by line, from the

transcriptions and later re-themed using the electronic data base Nvivo7 (Appendix 9 and 10).

The transcripts with themes written on each were then returned to each participant for comment and to have any erroneous data removed. It is important to remember that more than one interpretation can co-exist in an inquiry. This idea rests on Gadamer's (1975) supposition that understanding between two different beings occurs through a fusion of their horizons. The fusion is created through dialogue. Dismissing the idea that only one horizon exists opens up the possibility that more than one interpretation can exist of the same phenomenon. Ricoeur (1991) supports this idea, highlighting the intractable problem of plural interpretations that are open to several readings and to several constructions. Below are the stories that each carer told. The reader will note that the stories are emotionally driven and it was difficult for the participant to keep an affirmative focus without telling the whole story, necessitating a reflection of the difficult and traumatic times they had encountered. Each carer is referred to by their chosen code e.g. A1. I am referred to as P (A2 chose not to participate in this part of the study). Each of the carer's stories builds on the context and background literature to this study. Each of the stories is described singularly to capture the importance of struggling with problems and dilemmas of a day to day caring role. Later in the chapter the stories are themed using the affirmative data from the collective stories.

### ***Telephone Interview with Carer A1***

A1 was very matter of fact about sharing his story of caring for his wife with me. He is used to talking to others about A and how they had managed with her living with dementia. A1 was concerned about the amount of time that has elapsed since A received her diagnosis (and subsequently died) and that he wouldn't be able to recount an accurate memory of his feelings. I reassured him that his contribution would be valuable however it was told and to just go ahead and tell his story as it came into his head. The interview lasted for 45 minutes

and was audio recorded; I took notes alongside the interview and wrote a reflection of the experience after the interview.

A1's wife (A) died 6 years ago. He cared for her for 5 years and the last 5 months of her life she lived in residential care. It was important for A1 to be able to care for A throughout her illness and he initially managed this at home. They were married for 49 years 10 months. They lived in the suburbs of London in the family home and were both retired when A received her diagnosis of dementia (Lewy body dementia was diagnosed at post mortem). Getting and receiving the diagnosis was a lengthy and traumatic journey with the lack of a definitive diagnosis seeming to hang over them for the rest of A's life. A had little insight into her illness and A1 found himself in the position of having to make decisions for both of them when they were used to making decisions together. A1 found he was taking on the role of A as well as his own and that the practical day to day living activities were all his responsibility, as A became more dependent on him he found himself in the position of helping with personal care and supporting continence. He found this emotionally very difficult,

*'things like putting on incontinence pads were a struggle I used to say – just hold it A, and she wouldn't it would drop on the floor it was a struggle. I had to leave her sometimes to calm myself down and get myself together'.*

(Carer A1 telephone interview)

A1 had been in contact with an Admiral Nurse whom he built a trusting relationship with and he constantly referred to her throughout the interview when recalling feelings of wellbeing. When A was admitted to a care home he recalled the relationships he built with the professional staff at the home but also the importance of the relationship he maintained with his Admiral Nurse. To recall these well developed professional relationships A1 first told me about how difficult some the professional relationships had been. One example was when A

was receiving respite care. A1 explained that he was going out with his daughter and son in law but felt he needed to phone the respite centre first, he was told,

*'she is a bloody nuisance she keeps wandering.'*

A1 recalled,

*'this was a shock for me, the day centre saying they couldn't cope anymore.'*

The professional relationship A1 had built with the Admiral Nurse became very important to him at this time,

*'At the start of our marriage I promised never to put A in a home, I feel bad about it this because I did. It has helped me to talk about this J (Admiral Nurse) talked to me about it she said it wasn't my decision alone that helped.'*

A1's family relationships, however, were not displaced during his caring role and retold as a 'stabilising' relationship. A1 recounted how he felt the relationship between his wife and his daughter had not been allowed to develop in his daughter's early years due to caring commitments to his father in law. In fact he learned the contrary whilst A was in the care and that in fact they did have a well established and developed relationship that was able to reach far into A's progression into dementia. With the developing relationships between A and the care home staff A1 felt able to pick up his volunteer work and articulated how important he felt it was to give something back to the people that had helped whilst caring for A. After A died A1 became a member of Uniting Carers *for dementia*, speaking to other carers and professionals about his experiences and being part of this piece of research. He also kept in touch with the care home in a fund raising capacity until finally the time came to move on,

*'I have stopped now I needed to change the things I was doing.'*

Referring to my first notes after the interview with A1 I found immediate evidence of the importance of being able to 'give and receive'. The giving back was a large part of his feeling of wellbeing. This may be because it was a number of years since A had died and his life had continued to develop more outside the context of dementia. However, I felt that it should not

be ignored at this stage and may be something to return to later when co constructing the data collection.

This was my first telephone interview and having spent quite some time familiarising myself with the audio recorder, checking and rechecking it was recording sample conversations I managed to set it up incorrectly, thereby losing most of the data when the machine switched off 4 minutes into the interview. I had fortunately taken copious notes that I reflected upon immediately, as well as writing theoretical diary entries and a memo. As A1 was my first interviewee I had the option to re do the interview at a later date but decided on that day to record the data and store it until all the interviews were completed before asking for a repeat appointment. There were two reasons for this: firstly I did not want to put A1 under any undue pressure to retell his story, although he was used to talking to others about his caring experiences I did not feel comfortable in asking him at this point. Secondly, I had struggled during the interview not to approach the conversation as a therapeutic intervention but to keep to the interview questions with a minimal amount of intervention. Discussing this later with my first supervisor (24/01/08) helped relieve my anxiety of not conducting the interviews with a research focus but allowing my practice experience to inform my new role as a researcher. The decision was also made not to repeat the interview.

### ***Telephone Interview with Carer A3***

A3 is 50 years old and cares for his father, a widower who lives independently in his own flat. He is married with one 5 year old daughter. He works full time as a furniture designer and maker.

A3 started by describing the struggle he had with diagnosis,

*'he was diagnosed on the 22nd December 2004.'*

A3 describes this as an incredibly difficult stage, taking about a year before he became much more engaged with his father's life. This entailed gathering together letters and assessment information to try and make sense of what was going on,

*'it was quite early on but they didn't say it was Alzheimer's disease until much later when I got the piece of paper and traced the assessment back. It was much later when I got copies of the letters, later on and traced it back that confirmed the diagnosis.'*

The confirmation of a diagnosis then provided a platform of some stability for the family relationships to develop alongside the development of the changing relationship between A3 and his father,

*'umm things that went well or you felt relaxed ..... the period we have just gone through 2007 I have felt that we have all felt that the Alzheimer's disease has settled down. We have got used to the idea of Alzheimer's disease my dad is in a routine .....*

A3 described how life had settled down into feelings of acceptance, a routine for all of them. A3 recounted how introducing his father to his own friends and acquaintances had supported the closer family relationships. This involved the use of an immense amount of his own personal energy tracking down old friends of his fathers and introducing him to new friends that were established relationships of his own family. This helped relieve his father's feelings of isolation and loss due to the death of his own close friends,

*'one of the things that seems to trouble him a lot is – all of my friends have died – this I think is a yawning cavern .... when I go and pick him up we quite often come up onto a road where a friend of his had err a dress making workshop every time we come up this road he says I wonder what happened to S? So I tracked this man down via his daughter and other friends...'*

During the 'S' meeting he became empowered, they were both back in control they used endearments like '*you dirty old git*', there was a friendship bond. This second interview provided comparable data around the trauma of gaining and then receiving a diagnosis with the period following diagnosis being a time of relative wellbeing with time to develop existing, new and established relationships.

A3 seemed to be particularly perceptive to his father's relationship and communication needs. He went to huge lengths to secure a stable environment in which his father felt safe. The professional relationships he had built went some way to provide a period of stability and he had found his father's general practitioner particularly helpful,

*'the doctor is very important the doctor is someone who can give general help about dementia .... dad has known him for 25 years no sorry almost 30 years umm and he is actually outside the doctors catchment area the guy has let him stay on umm and he is remarkably supportive.'*

As for A1, this professional relationship was very important for A3, in feeling supported and relating this feeling to a feeling of wellbeing for him.

This second interview went much smoother and I felt I had begun to find my 'research role'. However, A3 had already thought very carefully about the things that went well or were comfortable in his caring role and needed very little prompting or developing of questions from me. He was very clear about the difficulty of getting the balance right for his father and the importance of having the right support, maintaining an element of control for his father and receiving respite. Frustratingly my struggle with the recorder continued; I managed to retain the whole recording but was dogged by background noise making it difficult to transcribe (from reflective diary 27/011/2007).

#### ***Telephone Interview with Carer A4***

A4 is 72 years old and has cared for her husband, L, for 10 years. They are both retired and live in North London. L has a diagnosis of Alzheimer's disease and he is now mainly cared for in bed by A4 who is supported by their family and social services. The home A4 share with L is a private space and they prefer not to have professionals visiting. At the time of the telephone interview there did not seem a way to keep their home private, as the support is

essential to L's care and A4's physical and mental health. A4 has a good understanding of Alzheimer's disease and its progression; before she retired she was a health care assistant. A4 reiterated the conversation I had with A1 and A3 about initially finding it difficult to think about feelings of wellbeing or when there were periods that went well and how their relationships supported this:

P: '*.....times when things went well?*'

A4: '*ummm quite honestly it has mostly been an uphill struggle, there may be have been a period of when things were most comfortable for me was before L stopped walking .....*'

She continually returned to the distressing times and experiences she had been through the most poignant of these being the feelings of intrusion on her independence and the intimate relationship she has with L within their own home,

*'it is an intrusion on my life I feel very tense before they come I am very independent and it is difficult for me .... also the wear and tear the extra dirt the extra work you have to you know it is not easy .....normally we shut our front doors and that is it isn't it?'*

L had often felt let down by professionals and the way she and L have been treated and the fact there has been no relationship built up between them,

*'There was a woman who is supposed to be but I have never seen her she has only phoned me twice in 3 years that you know and the CPN discharged us because she said the social services were trying to push L on to the National Health Service continuing care saying that they were not what did they call it? I can't remember now but .....*'

P: '*right..*'

A4 '*.... so she said the only way because at that point he wasn't actually as bad as he is now.*'

P: '*right...*'

A4: '*so she said I am going to discharge you so they can't do that and she did and I haven't had anyone since.*'

This conversation with A4 again highlighted the importance of continued and trusted professional relationships for the carer. A4 sounded frustrated when she recounted this part of her story and the withdrawal of services that may have been able to support her and L have further isolated her and compounded her feelings of having to cope alone.

A4 has a very heavy accent, which meant that it was sometimes difficult to understand her and hear what she was saying. She became tearful at times and it was clear that her caring role had been a real struggle. The sense of family support was important to her but it is also important that she supports the family relationships as family relationships not as carer relationships. She understands about Alzheimer's disease and its progression but it came over strongly that she appreciates services that are consistent with good communication skills. Honesty and a trusting relationship are also very important to her as a carer, values she did not experience when she was put in contact with professionals. Their home is a private place and they prefer not to have professionals visiting although there now does not seem to be a way round this for them as it is now essential to help with L's care (from reflective diary 27/11/2007).

### ***Telephone Interview with Carer A5***

Carer A5 is 65 years old and she is a retired day care unit manager. She has cared for her widowed mother for 8 years. Her mother has a diagnosis of vascular dementia, a heart condition and arthritis, but she lives independently a short distance from A5. A5 was quite nervous about talking to me wanting to get the facts about her mother and her caring role absolutely right. She had made notes before the interview using the guidelines I had sent. The main focus of her conversation was about the struggle she has with retaining her mother's independence so she can live in her own home. The professional care has been difficult to sustain:

P: '*Can you tell me about a time when things were going well when caring for your mum?*'

A5: '*One of the really major things was when I got a new carer which was about two and a half years ago umm I had carers prior and you could never quite rely on them then x came along and it was like a breath of fresh air to be honest. She was good you*

*know I could trust her and I knew things would be done, the way mum likes them to be done .....'*

I noted after this interview (reflective notes 26/11/2007): The professional help is not just about receiving a ‘service’ but the relationship is very important for the ‘service’ to be valued. The professional needs to know what the person likes and dislikes and build an element of trust with them and their carer. This appears to provide a period of stability for the carer.

A5 talked about times that she has spent with her mother that she values, for example when they went on holiday together which was a period of normalisation for her:

P: ‘*What was the best thing about that?*’

A5: ‘*I didn’t have the same responsibility as I do at home I know that sounds silly as I am with her all the time but somebody else is there and we were there together all day because we were on holiday doing different things she enjoyed. Happy and laughing meeting other people and being her normal relaxed self.’*

A5 had the same feelings of protection of the relationship with her daughters as A4 described with her family. Her daughters were on hand to help with her mother’s care but she is now reluctant for them to continue:

P: ‘*So is there anyone else who helps with your mum?*’

A5: ‘*Well I have my daughters I have three of them but we have to be careful because she can turn on a penny my second daughter used to do everything for her but then she started turning on her saying that she stole her clothes and stole money.*’

After the interview I reflected on how important it is to A5 to retain her close relationship with her mother and be a mother to her daughters, protecting them from the manifestation of the symptoms of dementia that her mother is experiencing. A5 required a lot of supportive conversation during the interview as she was quite anxious about talking about her experiences of caring for her mother.

### **Telephone Interview with Carer A6**

Carer A6 is 80 years old and she cared for her husband P for about 7 years. P was diagnosed with Pick's disease and suffered with many difficult and distressing symptoms. Both of them had retired from running their own business when P received his diagnosis. Their relationship had always been very close, working and running the business together with busy social lives. P had always been the leader in the relationship and A6 describes how things changed during her caring role,

*A6: ‘..you know that first of all Pick’s leaves a lot of mental acumen still there isn’t it certainly isn’t like Alzheimer’s or any of the other things and I found it much more difficult than other people seem to have caring for someone with dementia. I must tell you that we worked together my husband was a solicitor and we worked together for about 40 years so were used to being closeted together and he was always the leader and one of the things I found most difficult was the role reversal he was very noisy, extrovert and he became completely quiet introvert and I had to take over as leader. That was another thing that was very difficult.’*

Finding things they could do together was important,

*‘you are asking me about perhaps when things went well, we just had little bits before he refused to walk I used to take him for a 14 mile drive every day a round trip in the middle of it we went to xxxx and he fed the ducks and that sort of pleased me that he was doing anything at all.’*

The management of changing symptoms of dementia became increasingly difficult for A6 to manage as they fluctuated quickly without any notice,

*‘after a little while he said no, no that’s for children so we stopped doing that.’*

A6 then found other activities within their home,

*‘he loved listening to music over and over again and also one or two videos he used to watch constantly and that was sort of good for me and was a bit of a bonus.’*

I noticed that this description was similar to A3 when he was describing how he found completing activities with his father meaningful. Managing the changing symptoms of the dementia appears to be key here and A6 describes how her situation became much worse

until the intervention of an Admiral Nurse. P's symptoms had affected his behaviour causing a regimented regime and A6 was struggling to maintain this in their home,

*'everything was to the clock, meals had to be at certain times and exactly the same er lunch sort of had to be at 5 past 1 er and if I gave it to him earlier than that he looked at me as if something was wrong with me.'*

Having built a relationship with an Admiral Nurse, A6 agreed that she may benefit from a period of respite and P was admitted to hospital. The period of respite was extended (not specified at interview) and this affected her confidence in caring for him at home although the bonus for her was that the regimented behavioural patterns had stopped,

*'when he eventually came out of hospital er reluctantly he seemed to find it like a security and he went backwards and forwards quite a lot ..... he used to ask me to take him back at sort of 5am and I used to plead with him to stay at home.'*

This was clearly a very emotionally difficult time for A6 as she desperately wanted P to be at home with her but he found the security of the hospital environment comforting. A6 was very stressed at this time,

*'I found it impossible to relax it was very difficult 24 hour call very difficult nights umm and for a long time I didn't even sleep in a bed.'*

P was suffering from hallucinations and paranoia synonymous with Picks disease but A6 didn't understand what was happening at this time compounding her stress levels and feeling that it was her fault that P was suffering in this way. There was pressure from the hospital for P to return home. Through his behaviour he clearly demonstrated that he did not want to be discharged making the situation emotionally very tense and difficult. A6 continued with her relationship with the Admiral Nurse and after about a year P was admitted to a culturally sensitive home where he spent the last 11 months of his life. A6 felt comfortable with this supported decision and went on to attend the Admiral Nurse support groups, eventually talking to the group and their networks about her situation when caring for

P. Compounded by P's difficult symptoms and behaviour they lost many of their friends and became very isolated,

*'friends disappeared as if we had the plague.'*

However family members kept in touch reflecting the same relationship boundaries of the previously interviewed carers. A running theme throughout the interviews was the ability to sustain family relationships as son, daughter, mother etc and not turn them into caring relationships. Newer relationships, many professional, were introduced to A6 and P and several failed due to P's paranoia, leaving them isolated and unsupported for respite.

Organisations that supported well took time to build the relationship slowly, at the pace that was right for P and A6. These were professionals who they could trust, who valued them as people and had knowledge and skill in dementia care,

*'when he thought I was out of ear shot he said to her (care worker)are you going to take all your clothes off for me? and she said, no, no it's a bit cold today Nothing would have phased her, no.'*

A6 recounted how her relationships with the staff in the home where P lived were very important and she maintained them after P died,

*'I am still friendly with a lot of staff even though he was there for a relatively short time 11 months.'*

A6 identifies the themes of professional and family relationships and being able to share with others as important. These relationships highlighted the necessity for shared values and attitudes to be able to manage P's difficult and changing symptoms of dementia. She struggled with practical day to day activities during the period of P's regimented behaviour, becoming anxious about meals and eating. Support at this time became crucial to her wellbeing. I noted in my reflective diary (28/11/07) how A6 kept talking about the feelings of wellbeing during her caring role even though her voice broke frequently and she clearly found it difficult in places to recount her story.

### **Telephone Interview with Carer A7**

Carer A7 is 52 years old, married with one daughter and working part time. She cares for her mother (AB) who is married to BB and lives in a care home. She has cared for her mother for 5 years initially at home and more recently in a care home. BB found his wife's diagnosis of a mixed Alzheimer's disease and vascular dementia very difficult to manage. A7 related this to his very 'rocky' relationship with AB, and his 'inability to discuss things'. She describes in the interview how she feels her mother is owed the best care by her father and when he was at a point when he was not going to be able to do that she took the role of primary carer. She also makes sure her father has all the care he requires as he now lives alone. A7 began the interview by talking about how she thought hard about the questions not realising that her feelings had actually changed since she began caring for her mother. The relationship with her mother appears to have insidiously over taken her own personhood,

*'I wasn't really sure if that related to me now or whether that related to things since mum became unwell. ummm what I did was think about both really.'*

She went onto explain and rationalise her feelings through talking about trying to keep her relationships with her husband, daughter, mother and father "normal." Some space and time for herself was very important in A7's story to enable her to sustain her role as a mother and wife,

*'One of the things I have found it is when I go and see mum umm it is quite nice to have an hour or so just to wind down from any of the issues you might have dealt with whilst you have been there so when I get back home I am mum and wife and everything is fairly normal.'*

A7 retained the reciprocity of her relationships and her obligations of kinship role and affection with the support of the care home her mother now lives in.

Before her mother's admission to the care home the kinship and affection within her relationships were hard to sustain. The time and pressure on the family to find a care home was stressful,

*'I was not prepared just to let her live anywhere because it was a space social services wanted to fill up.'*

The search for the right home was supported by an Admiral Nurse and the relationship built with A7 was very important to her during this period. The Admiral Nurse was able to work with her to increase her confidence about her knowledge of dementia and related practical interventions. She related to the time of her mother's admission to the care home as a time of wellbeing,

*'for me the historically one of the things that made the biggest change in my life was my mum going into care umm because she spent a year being diagnosed, umm medication being withdrawn, and the scramble to find a placement ..... I knew once she was in a home I could start to relax about her daily hands on care in a sense.'*

Once her mother was settled into the care home A7 strove to repair other family relationships. Her daughter had become distressed after visiting her grandmother on a mental health assessment unit and she was keen to repair the grandmother/granddaughter relationship as soon as possible,

*'she was very close to my mum and we took her to see my mum in hospital once which was a mistake.'*

Once settled into the care home however A7 found an opportunity to repair the relationship, *'xx is a friendly place and we've started taking her err to some of the open days they have a party they have a Christmas party so she could run her own cake stall to raise money and that was how we got her seeing my mum again and it works fantastically well.'*

Her father had also become disengaged during the process of finding a care home and although the relationship was not historically good A7 found time to involve her father as much as possible. She introduced him to the Admiral Nurse and although this was not an ongoing relationship it was a bridge to the relationship between husband and wife during the transition between home care to care home care. A7 had quite quickly taken on the role of

primary carer for her mother due to the tension in relationships and her abilities to manage the practicalities and organisational aspects of the lives of her parents and herself,

*'I had a good relationship with my mum but unfortunately my mum had a bit of a bumpy relationship with my dad and when she first became ill I think it was quite obvious that he was not going to be able to take on board umm her care which is why I stepped in picked up what was kind of needed.'*

The past relationship between A7's parents has been difficult for her to manage, she found support in the Admiral Nurse and attempts were made to improve the relationship between her and her parents. In some ways this was helpful as it retained an open dialogue between A7 and her father and he now visits his wife in the care home; however the relationship remains tense at times.

A7 also highlighted the importance of being supported with the practical day to day caring role such as form filling, telephone calls, finding out information, co-ordinating care. Her sense of wellbeing whilst trying to manage this multitude of tasks was at times overwhelming and the feelings of responsibility remain with her now her mother is in care,

*'You don't always need to have someone to talk to but the experience of looking after err caring for a family member with dementia is hard, it is very tough on everybody I don't think its ... it is necessarily matters what the care setting is I have no less responsibility my mum's care even if she doesn't live with us, I manage her legal affairs and her financial affairs and umm buy her toiletries anything, anything that needs doing it is almost as if she is another one of my children.'*

The support she received from the Admiral Nurse helped her to retain her own identity, relieving the feelings of great weariness and complexity,

*'What is most difficult in the beginning because you almost lose your identity because so much of it is tied up into trying to sort out what is a very difficult situation.'*

A7's situation differed from the previous carers when relating her family story. The relationships were already unstable and she strove to stabilise them as well as caring for her mother. The transition from home care to care home care went some way to supporting this

and once her mother was settled into the care home the family relationships began to find a stability. The relationships have ‘moved on’ with a feeling of stabilisation within the family so they are now all able to visit her mother and contribute to her care within the care home environment.

### ***Telephone Interview with Carer A8***

Carer A8 is 67 years old. She had met her husband in Ghana in 1957 at school and they have been together ever since. She has cared for her husband (T) for three years; he has a diagnosis of Alzheimer’s disease. The process of gaining a diagnosis and assessment was long and traumatic taking many months. A8 explained how she had tried several times to get her husband to attend his GP surgery. Once the GP sent them away advising a vitamin supplement, on the second visit the GP asked T how he was and when he replied that he was fine advised T make a return visit alone. This did not happen and A8 remained constantly worried about her husband’s cognitive decline. Shortly after these visits T went missing for two days and was badly injured in a road traffic incident. The injury to his leg was not diagnosed for several days causing T and A8 great distress and several return trips to the hospital. T became so distressed from the pain he suffered that he was labelled aggressive and admitted into a mental health assessment unit where he was diagnosed with Alzheimer’s disease. A8 found this very distressing to recount and became tearful. Her distress required validation and support throughout the interview, prompting more questions than I had used in previous interviews. After his admission to the assessment unit T was admitted to a care home setting due to A8’s now poor physical health. She had been admitted to hospital during this time. Her feelings of loss were quite overwhelming during the interview, with tears and a heavy accent making the transcribing quite difficult.

The interview was very distressing and continued to be distressing when talking about family

relationships, despite these remaining strong and very supportive. A8's 4 children take it in turns to visit their father and relay information back to their mother when she is too unwell to visit. When she is well she makes the 20 minute car journey 2 or 3 times a week or an hour by bus when there is no lift available. She tearfully described how their friends no longer visit T as they find it too upsetting. She had however started to make tentative relationships with the care home staff, visiting to help with personal care and mealtimes when she could,

*'I try and do things for him you know cut his nails and clean his teeth and so on, yes.'*

As the interview had been particularly difficult and distressing for A8 I re phrased one of the questions,

P: *'What could have happened to make this time better for you?'*

A7 *'actually at Christmas time I am having him home yes one of my daughters she has got twins she lives in xxx and it is nearer where my husband is so she wants us all of us to come for Christmas so I have arranged transport to come and pick him up and then we are going to take him back at 6 so he is going to spend the whole day.'*

The transition to care home care has clearly caused A8 great distress and the telephone interview came at a difficult time in her caring role. Following the interview I asked the co-ordinator of Uniting Carers *for dementia* to contact her to make sure she was still regularly seeing the Admiral Nurse who had developed and maintained relationships with A8 and her family.

### ***Telephone Interview with Carer A9***

This recording was hardly audible due to a heavy accent and background noise on the telephone line so I have used my notes taken during the telephone interview with reflections from my diary. A9 is 58 years old and she has cared for her mother who has a diagnosis of Alzheimer's disease and arthritis for 5 years. She gave up work to care for her mother at home. A9 had made careful notes about the times she had felt things were going

well and I have continued with the same theme to retain her feelings throughout the interview.

P: '*When do you feel things were going well or that you were feeling comfortable?*'  
A9: '*The Admiral Nurse had time for me we had a one to one meeting for an hour this was very valuable. I had somebody to advocate and I felt safe. The Admiral Nurse was calm with an all embracing personality, could answer things, educate, was non-judgmental I trusted her. Working with the Admiral Nurse works physically as well as psychologically. My blood pressure went up after the Admiral Nurse left.*'

A9 built a trusting and honest relationship with the Admiral Nurse but after the nurse left the service she did not feel she could contact them again and joined a carers group. She found this useful for exchange of information and sharing of problem solving strategies. Her mother was admitted to acute care for a period of time which she describes as most stressful. It was difficult to form any relationships with the professionals and she felt isolated from her mother's care, worrying that she was not being looked after properly. She found the environment hostile and non communicative compounding her feelings of isolation. She recounted how different the approach and care was in Accident and Emergency and critical care where the professional staff were excellent at exchanging information and keeping her up to date about her mother's care. The professional relationships were very important to A9 as she had retired as a care worker to care for her mother. She has a good knowledge of dementia and is articulate and confident. However, she found she was feeling marginalised and disempowered with the lack of engagement by some professionals. She feels she has the right expertise to be able to care for her mother as she can nurture their relationship. She uses her skills in communication to talk to other people about dementia, to gather information to help care for her mother and to liaise with professionals about care and services. This experience is not unlike the previous carer's transcripts and validates the feelings of disempowerment that can occur when professionals do not communicate effectively with carers. This compounds the feelings of stress for the carer giving rise to anxiety about the care being delivered to the person with dementia.

A9 also values the relationship her son has with his grandmother and she described him as “a pillar of strength”, whom she can rely on to help her. In the relationships that A9 describes she discusses the ability to share information, trust, values and attitudes. Where the people she came into contact with were unable to fulfil this she was left feeling stressed and isolated.

### ***Interpreting the data***

When I began the telephone interviews using an appreciative inquiry approach it seemed to be distracting to the carers to be asked to think of times of comfort and well-being in their caring role. This took careful handling at the beginning of each interview as I did not want to be dismissive of the problems, stress and burden they had experienced. It became evident from the first interview with A1 that it was necessary to relate times of distress to be able to recall times of wellbeing and comfort. I found this way of relating a carer’s story similar to my experiences in clinical practice and my personal life. We do not dwell on the hard times but if someone is interested in us as person we relate the whole story. To be able to do this we require elements of a trusting relationship, whether it be a professional relationship or a family relationship. As I facilitated the interviews I became aware of how important relationships were to the carer but there were other elements of the relationships that were dependent on the emergence of feelings of wellbeing. I initially theorised about ‘giving and receiving’ and how the action either practically or emotionally was giving stability to the wide range of relationships the carer was part of. The diagram below is taken from my theoretical diary 22/02/2008. The development of the transition from ill-being to well-being is shown in 3 stages; each stage can overlap and be returned to many times throughout the caring trajectory. The data ‘giving and receiving’ is taken directly from the transcripts of the telephone interviews.

### ***Balancing the need for ‘giving and receiving’:***

*Relationship is stable:*

Before symptoms of dementia (pre-diagnosis) the scale is balanced; times of conflict and trauma stabilise themselves out between the carer and the person with dementia, family and significant others. This does not necessarily mean that the relationships are harmonious but the person with dementia and their carer manage and develop the relationships with family and significant others to reach a level of well-being. To reach this level there has to be mutuality within the relationships.

*Relationship becomes unstable:*

As the symptoms of the dementia progress; the mutuality within the relationship between the person with dementia and the carer begins to change, reaching a critical point when help and/or support is required to stabilise the relationship. This may be in the form of practical or emotional help and is often from a family member or significant other. As the situation becomes more complex, for example balancing changing behaviour and/or physical needs the need becomes higher. This is when professional help is often requested by the carer or introduced as an emergency intervention (for example an admission to hospital) for the carer or person with dementia.

*Relationship stabilises again for an unspecified amount of time:*

To support a return to a period of stability in the relationship with the person with dementia the help or support for the carer becomes crucial. The balance swings throughout the caring trajectory and requires stabilising at differing points, individual to the situation. The transcripts were then re read to examine the context of stability in relation to the carer's relationships using four themes: stabilising the relationship between the carer and the person with dementia (1); stabilising family relationships (2); professional relationships that stabilise (3) and stabilising relationships to move on.

## 1. Stabilising the relationship between the carer and the person with dementia

The following reconstructions of the carer's stories recount times of stress or unbalance of their relationships with the person with dementia, their family and professionals. Each reconstruction builds on the theoretical development of finding a stability that will support feelings of value and wellbeing for the carer.

A1 described how lonely and difficult it became for him to look after his wife. He managed alone for about three years before he was introduced to an Admiral Nurse who he built a good relationship with. During the three years, however, his relationship with his wife had become strained and difficult. Past promises were becoming difficult to keep,

*'At the start of our marriage I promised never to put A in a home I feel bad about this because I did. It has helped to talk about this to the Admiral Nurse she talked to me about it she said it wasn't my decision alone, that helped.'*

He described the relationship he built with the Admiral Nurse as a value that enabled him to continue his caring role and eased the guilt of searching for and later taking up a placement in a care home for A. At the time he met the Admiral Nurse the closeness of his relationship with his wife was changing to become task orientated and frustrating,

*'things like putting on continence pads were a struggle I used to say 'just hold that A' and she wouldn't it would drop on the floor it was a struggle. I had to leave her sometimes to calm myself down and get myself together.'*

Things became so difficult in stabilising feelings of wellbeing for the two of them nursing home care was decided:

*'A going into a home was relief.'*

It is hard to capture the feelings in an interview on paper and include the emotion that was within these words. A1 talked about the difficult times, expressing feeling and emotion and

showing how the complexities of his emotions and feelings from that time are still with him six years on.

A4 values her close relationship with her husband preferring to complete personal and intimate care herself. She talked about this time as quiet and intimate, a time when she can use touch and soft words to communicate with R. This is often an area in a husband and wife's relationship that is lost when someone has dementia, especially if personal care is given by professionals. Intimacy is also an area that is ignored by professionals or in some cases even frowned upon. A4 had managed to find her own personal stability in being able to keep intimate relationships with her husband but, as she explains below, this was cost of having professional services to support her:

*'it is partly a bit of intimacy and that personal very personal sort of what do you call it that routine in the morning it is partly due to the carers they do not do it to my satisfaction really you know there is that question to it is a very private thing as I said I used to do everything myself but now I find I have to accept I cannot do everything but that is very important I have already wash him the way he likes it I know his likes and dislikes, I chat to him when I feel like it.'*

A5 expressed how she values the close relationship with her mother and talked about times when they have been together that they both enjoy:

*'Another time when it was really good was when I took mum on holiday I used to do that every year that was nice leading up to that seeing her getting quite excited about going away, it was nice being away.'*

'Mum' had recently been in hospital with physical problems and on her return home A5 experienced a very difficult period. Mum was disorientated and very frightened finding herself alone in her flat again. She was telephoning A5 periodically through the night:

*'Well the first week the first couple of nights she was totally terrified but umm she has now got back to normal she is quite ok now.'*

This was a difficult time for their relationship as it put a strain on A5's emotions and time. The care package that had been organised from the hospital was erratic and unreliable; A5 found herself wanting to be with her mother all the time in order to keep her safe. Maintaining the closeness in her and P's relationship became very difficult for A6. She found his difficult and distressing symptoms severely restricted what they could do together. She went to huge lengths to enable them to do things together as this was important because they had spent more than 40 years living and working side by side. Here she describes a time that provided some stability in their relationship,

*'you are asking about perhaps when things went well – we just had little bits he refused to walk I used to take him when he was able to walk. I used to take him for a 14 mile drive every day a round trip in the middle of it we went to the Serpentine and he fed the ducks and that sort of pleased me that he was doing anything at all.'*

She also found things to do together that they both enjoyed or that relieved some of P's symptoms when they were at home.

*'He loved listening to music and that helped me give me a sort of when I could wash and he listened to the same music over and over again and also one or two videos he used to watch constantly and that was sort of good for me.'*

Other times the situation became much more difficult putting a great strain on their relationship. She recalls when P was very regimented in every task he completed.

*'he had very, very regimented behaviour before that he had to do everything to the clock, meals had to be at certain times and always exactly the same and er lunch sort of had to be at 5 past 1 er and if I gave it to him earlier than that he looked at me as if there was something wrong with me.'*

At times things became so difficult A6 found her feelings for P were changing out of all recognition:

*'I felt that I was well it is a living bereavement um and I felt um that wasn't my husband and I was looking after someone and I was almost like a nurse and I really didn't know him and I often didn't like him.'*

A7 found that she took on the larger proportion of the care for her mother due to the relationship she had with her father. As her mother's dementia progressed there were a lot of practical arrangements that required organising as her father was struggling with these,

*'I had a very good relationship with my mum but unfortunately my mum had a bit of a bumpy relationship with my dad and when she first became ill I think it was quite obvious that he was not going to be able to take on board umm her care which is why I stepped in picked up kind of what needed to be done.'*

Many months were spent finding the right care home; A7 found this difficult and stressful as she wanted to find the place that felt right for her mother,

*'It just felt as if it was home from home, and that's what I really wanted for my mum I wanted her err happy about where she was. It was very clean the food was very good there was an entertainments programme, activities outside of the home during the year err and people were responsive.'*

Apart from the practicalities of how the home is run, the environment and where it is situated it was important that the staff had an understanding of AB's past life, culture and experiences.

*'The other thing that was important as well my mum is Italian and I really wanted her to be somewhere where if she lapsed, if she ever lapsed language wise that they would take that on board.'*

A8 recalls the difficulties she had getting her husband to see their G.P and when she did get him to a consultation how let down she felt by the process,

*'My GP sent me a letter to be reviewed I said to my husband oh come lets go together so when we went I said here is my husband and the GP turned round and said how are you? My husband said oh I am fine and then I told the GP about my husband and you know he got annoyed and he turned to my husband and said if you want you can come back and see me? I turned to the GP and said no, if somebody is not well he won't come back and see you I live with him so please refer my husband which he didn't he just let him go.'*

Her experience continued to be painful and long all the while T's condition was deteriorating until,

*'2 months later my husband got lost he was missing for 2 days he was knocked down by a car he was, he got injured he went to xx 28 miles away from home so when he was admitted as an emergency the nurse rang to tell me my husband you know that was about quarter to 9pm the police were involved in searching for him we were all searching for him we couldn't find him.'*

T was taken to an acute hospital for emergency treatment and when he returned home the same day he could not weight bear and had to return for further x rays where they diagnosed a fracture to his leg. He was admitted to hospital for treatment to the fracture then discharged home,

*'I got him home and he was you know his attitude was very, very bad shouting and screaming and then we went back again to the hospital because the plaster was too tight they took it off and then the hospital couldn't take it so they sent him to another hospital and he was diagnosed properly with Alzheimer's Disease.'*

The 'bad behaviour' T was showing was a symptom of his injuries. Unable to express pain he had no other way of communicating. A8 found the whole experience extremely difficult and emotionally upsetting. She became tearful whilst remembering this sequence of events and required some thoughtful conversation before we continued the interview. A8 recalls this period of T's care as very distressing and supports the findings of the this review that the attention T received diminished with his escalation of shouting and disruptive behaviour, lengthening the time he remained in distress.

## 2. Stabilising family relationships

Maintaining and seeking stability of family relationships was evident throughout the data. Family relationships remained intact with involvement from A1's daughter, son-in-law and granddaughter. This brought him comfort and was described as being valuable,

*'My daughter used to visit. My son-in-law less often he has his own business so he visited at weekends it was difficult. My granddaughter used to visit regularly as well she is a podiatrist she used to look after A's feet. It was nice to know that my daughter was visiting; she wanted to help look after her mother.'*

A1 described the feelings he had when he realised that a close bond had always been evident between his daughter and her mother,

*'They didn't have a chance to bond when she was a small child. My father in law returned from America with bad trigeminal neuralgia (he was treated at the London Hospital; they severed the nerve this left him with facial paralysis). My mother in law adored babies and she looked after my daughter whilst A went to many hospital visits with her father. I though the bond between A and my daughter hadn't been properly formed but I know now that it had.'*

Reflecting six years later, A1 sees the resolution of this relationship as of value and described his feelings about how without his wife having dementia he may never have known this. He now places value on the feelings of wellbeing this gave him, highlighting that relationships can be stabilised even in the most difficult of times.

A3 described a comfortable relationship with his father following the more difficult period of diagnosis and assessment. He talked about how he values the fact that he has managed to integrate his family and work life into a routine that includes caring for his father. During the week his father lives in his own flat in another area of London. He stays with A3 and his family every week end. A3 has incorporated activities and socialisation into each weekend to include things that they both enjoy doing together like meeting friends in the pub.

*'We always have this thing which is almost becoming a joke in the pub now when we ask for a pint and a half of Guinness from the person serving the bar man says £4.20 and my father says "WHAT! that price" and I say that way it is now pa and we will settle down. Quite often this is a time when he will come out and talk just the other day a friend of mine came up and engaged you know with us and you know these are moments when he starts to come alive are really quite ..... I know he enjoys it so that is one bit a sort of high point to our week and if he comes on a Saturday we might do that twice over a weekend.'*

He also describes times when he feels tired and worn out but the strong relationship they have is supported at these times by using touch as a form of intimacy. He values this as part of their father/son relationship.

*'.... if I am worn out just an arm round him or 2 arms round him. Trying to make a political manifestation that I am there for him it is a part where we are probably tied up in our own stuff.'*

A3 has placed his family firmly at the centre of his father's care. He has managed to integrate his caring role into his day to day family life by building on those relationships.

*'.....he comes to us for the weekend. That is something I think gives him great happiness at the weekend he has a chair in the ground floor room which is our kitchen and living room in the middle of family life which he likes.'*

A3's father has known his wife for 12 years. A3's wife finds communicating with her father in law comfortable in a space that they all feel an ownership to as home. A similar relationship has been developed with his daughter. He describes this relationship as a '*no challenges*' relationship, '*bonny in play*' where the two of them laugh and are comfortable as themselves. He values this warm and comfortable atmosphere they share that is trusting and has continuity.

A4 has two step children and the relationship they have with them is particularly important. She highlighted that it was of great importance to her that the relationship remains one of son or daughter and not of carer. In the interview she described the children's feelings towards their father, which she found comforting. She has requested that these are not included in the thesis as they are her direct thoughts not theirs.

*'they come once or twice a year yes they are daughter and son ..... and all fairness to them they do love R they are there they know he is their dad.'*

Before L was diagnosed with Alzheimer's disease they had a large network of friends. As L's dementia has progressed the network has got smaller. A4 explained that she felt that men do not have the same sort of relationships as women and that her husband has always felt more comfortable with a practical sort of relationship; for example, a relationship where he

shared a drink or a game. She now tries to meet friends during her respite time meeting for a coffee and catching up with news,

*'Our friends do not live near we used to have lots of friends and lots of people seem to have dissolved somewhere we have a handful of old faithful friends and also they are getting older themselves.'*

A5 has 3 daughters who help with their grandmother's care. More recently the symptoms of her vascular dementia have been difficult to manage. This was probably due to her physical condition as she was admitted to hospital in the same period 'Mum' accused one daughter of stealing and became distressed if she tried to visit or help her. This put a strain on the relationship between granddaughters and grandmother leaving A5 without her family support with the practical day to day caring.

*'Well I have my daughters I have 3 of them but we have to be careful because she can turn on a penny my second eldest daughter used to do everything for her but then she started turning on her saying that she stole her clothes and stole money.'*

Because P had very distressing symptoms, A6 found that their friends gradually 'disappeared'. She understood in a practical way that it was hard for people to manage the communication difficulties with P but felt emotionally very hurt and isolated,

*'Friends disappeared as if we had the plague; P's sister visited him constantly and my own children I have 3 children they were very supportive.'*

Close family relationships were maintained providing an important source of comfort and support.

A7 found the relationship with her father difficult to manage at times and struggled with the location of the care home and maintaining her past relationships. Coping with living a distance from her parents became a juggling act between maintaining her relationship with her husband and daughter and that with her parents.

*'At the time I couldn't decide whether it was appropriate for mum to live closer to us so that I could see her more often or whether she should stay in xx and be closer to my father and her friends who she had worked with.'*

She included her parents in the decisions for the future checking out with them where ever possible that the decisions were the right ones for them.

*'I took my dad to see it so he had met some of the people umm he found it very hard and still finds it very hard to be able to acknowledge and deal with my mother's illness but I felt it was important for him to see where she was going to live.'*

At the same time she was supporting her daughter's relationship with her grandparents. She found practical ways that her daughter could be included and feel that she was contributing to the family relationships:

*'My daughter obviously was much younger at the time and she found it very hard to take on board what had happened to my mum she was very close to my mum and we took her to see my mum in hospital once which was a mistake. With hind sight we should not have done it, but the care home is such a friendly place and we've err we started taking her err to some of the open days they have a party they have a Christmas party and we umm she could run her own cake stall to raise money and that was how we got her into seeing my mum again and it works fantastically well.'*

T is now settled into a care home. As A8 has been unwell and in hospital herself she has not been able to visit regularly. She misses T very much. The interview took place near to Christmas she described how she was going to bring him home for the day with his family,

*'actually at Christmas time I am having him home yes one of my daughters she has got twins she lives in xx and it is nearer where my husband is and so she wants all of us to come for Christmas so I have arranged for the transport to come and pick him up and then we take him back at 6 so he is going to spend the whole day.'*

She values her family relationships and without them she would have become more distressed and lonely. Her children have been able to visit and relay their thoughts and feelings about the home and their father. This has helped A8's feelings.

*'The children yes they are all taking it in turns to go I went yesterday I haven't been well for the past two weeks.'*

She also found value and comfort from friends, who have helped with the communication and contact with T,

*'He has 3 or 4 visits a week his friends and you know my friends and his work colleagues ..... but when they go and visit he goes and gets upset and then they won't go again because they are too upset ( A8 is Crying ).'*

A9 talks about her relationship with her son and how supportive he is with his grandmother's day to day care. She described the 'bond' they have that allowed him to feel comfortable when he engaged with his grandmother in order to complete tasks like changing an incontinence pad. A9 was particularly grateful for his help with continence issues.

*'My son is very supportive he is the gap he steps in. He is a pillar of strength (29years old) quite caring and has a bond with his grandmother. He helps with the incontinence.'*

### 3. Professional Relationships that Stabilise

For professionals to provide valued support to the carer and enable the process of stabilising; the relationships the carer had with the person with dementia, their close and wider family members and other professionals all had to be taken into consideration. A1 was able to recall the relationships that gave him a sense of wellbeing with professionals very well. This may be due to him feeling relieved when A went to be cared for in the nursing home. Before he was able to recall this he recalled a negative experience he had earlier on in his caring role,

*'She had respite there this upset me, I was told to go away and enjoy myself. I tried to I was going out with my daughter and son in law. I phoned before we left to make sure everything was alright. The lady said 'she is a bloody nuisance she keeps wandering.'*

With support from other professionals he was able to make the transition into care home care. He talked about this time as being one of the best. He was able to trust the care staff and built a trusting relationship with the Matron,

*'the Admiral Nurse came in she would talk to us both mainly me. I felt a tremendous relief to have someone to talk to. The Admiral Nurse channelled me through the services, she arranged for a carer in the morning and that sort of thing.'*

The Admiral Nurse was able to talk to A1 about how he felt without judgment, enabling him to make a decision about engaging with other professionals and services. His future relationships with professionals improved and became trusting enabling him to make decisions about his own life. The importance of the professionals taking time and getting to know A was very important. A1 valued the cultural relationship the matron formed with A,

*'Matron had been there a long time she was Srilankan, she made a close relationship with A. A felt comfortable as she grew up in Srilanka and lived there until she was 9 so there was a bond. She liked the carers there too some of them were Srilankan the rest from Asia.'*

A3 described how he has had conflicting feelings about the professional relationships he has developed. As 'Dad' lives alone during the week, professional services have gradually been introduced to him. This has not always been easy due to his fierce independence and the lack of time to form relationships with each person involved in his care. They have found that care workers do not work with any continuity. When they are able to form a relationship with their client they are often moved on to a new client. The wider family is rarely involved with the selection of care workers, making A3 feel disempowered and removed from the active caring role during the week. A3 feels he has so much to share about his father that some of this knowledge would be useful when they visit.

*'I wish you could talk to the carers the company are going to provide to build up a relationship it could be a lot more intuitive.'*

One relationship he does value is with his father's G.P.,

*'The doctor is very important the doctor is someone who can give general help about dementia umm my dad has known him for 25 years no sorry almost 30 years um and he is actually outside the doctors catchment area the guy has let him stay on umm and he is remarkably supportive he ..... he is just remarkably helpful in an overseeing way and I know my dad has really accepted the medical ... a tricky thing and was a chalk mark in his relationship.'*

This shows the importance of continuity and the building of relationships between professionals and the person with dementia and their carers/families.

A3 also highlighted the importance of valuing the person with dementia's past life. His father showed a reluctance to engage with services until a flexible approach that valued his past contribution to the local community was acknowledged.

*'My dad was the sort of person who used to belong to the neighbourhood support team and would um spend an awful lot of time caring for others and what I discovered when we turned it round the other way so that they were coming for him it was rejected and one of the tricks that um seems to work with him that when people come into see him they ask his advice.'*

For A4, engaging in services meant an invasion to the privacy of their home. She found little flexibility in how the services were offered and when she did finally engage and make relationships the service stopped. She found what seemed to be the 'entertaining' part of connecting with so many people entering her home a burden. She preferred to have the house in order be washed, dressed and communicate with the professional in an entertaining sort of way for example; meet and greet, offer refreshments and finish the visit with a farewell. The regimentation of how the service was provided left her with little respite time as she felt continually anxious about the next visit.

*'... um it is very regimented and you have to answer the door and do the nice bits not that they are not nice people the carers are nice people but it is an intrusion into my life I, I feel very tense before they come I am very independent and it is very difficult for me.'*

When professional relationships were closed; for example, in A4's case when the person in question left their post, she found the lack of replacement disappointing and rejecting to the relationship she had built up.

*,she was my mentor you know she used to come for me I could talk we used to meet every 2 months maybe something like that for 20 minutes half an hour something like that whatever but it was very helpful first of all she was very informative and secondly she was fantastic actually. She had really very practical very pragmatic approach to everything and she was great but then she left and I haven't really had anybody.'*

She did, however, find that professionals who visited for a longer period of time were beneficial as they gave her time to engage with them for herself and as a result, over time she felt confident and at ease.

*'they are lovely the care workers are very good, when our regular person is on holiday they are all very nice I feel confident with them especially with the person who comes on a Wednesday they have to feed R. R is very, very difficult to feed. I feel quite confident he has the patience it is very important it helps it is very important.'*

The reliability of professional help was very important to A5 as she lives a distance from her mother. When the person visiting built a relationship with 'Mum' and got to know her likes and dislikes, things went well; allowing A5 some time for herself and allowing her emotions about keeping her mother safe in her own home for as long as possible subside. The continuity, flexibility and accessibility of the professional were very important.

*'I had carers prior and you could never quite rely on them then (name) came along and it was like a breath of fresh air to be honest. She was so good you know I could trust her and I knew things would be done, the way things mum liked them to be done.'*

She found that when the professional could not be relied upon the element of trust went; placing stress and burden on A5 as she had to 'check' that the care has been given.

*'the carer I have got at the moment she doesn't really do the sort of things that she is supposed to be doing, she is a very nice person and mum likes her but ummm I still have to do things so I still go round in the mornings.'*

Risk was a particular worry for A5 as her mother lives alone. She described her feelings when the element of trust and reliability was failing,

*'I know they can't all the same but it trusts someone to do things in the house. Like safety is important like she goes out with her handbag, her keys in her handbag and sometimes that doesn't happen. So I have to make sure I am at her home you know when she comes home otherwise she can't get in.'*

The feelings remained with A5 all day until she could contact her mother or the day centre to make sure she was safe. A5 described how stressful this was and often questioned whether it

would be better to deliver all her mother's care herself. She realised that would increase her time with her mother but that their independence and privacy is important, even though they do have a very close relationship.

P had several admissions to a mental health unit due to his distressing symptoms. These admissions made A6 feel guilty but did provide the positive aspect of time for self and recuperation. She found it very difficult when P wanted to return to the hospital, feeling he felt safer there than at home,

*'when he eventually did come out of hospital er reluctantly he seemed to find it like a security and we went backwards and forwards quite a lot like he used to come home on leave as they call it and he would ask me to take him back at sort of 5am in the morning I used to plead with him to stay at home and he used to say no, no I must go.'*

Whilst the periods of admission provided respite, especially at night, A6 still spent many hours with P during the day.

*'Well it certainly gave ..... I spent at least 5 hours a day at the hospital the whole of the visiting time it was in a mental health unit and um actually I felt happy that he was being looked after and also you get to know people they seem to have regular visits and I was sort of doing a ward round every day when I arrived because I had to ask everyone how they were and we did go out within the hospital grounds or I could take him for a drive but he always wanted to be back at the hospital. Once one of the doctors said to me why is he back here? and I said well it must be something about your personality that I don't have.'*

After an unspecified amount of time A6 was introduced to a professional to work with her and she describes below the relief she found in having someone to work with.

*'I found it absolutely wonderful the Admiral Nurse who came to me initially just sort of turned up on my door step she was sent I think by the hospital and she absolutely saved my life I didn't know what to do or how to cope or how to manage and she was always available and she said if you want to scream at somebody just scream at me on the telephone.'*

Once she became more confident talking about her experiences with P she joined a carers group.

*'Then I did attend several care groups one of the groups was the group the Admiral Nurse ran in the area and I still attend those groups and the other one was at xx care and I did attend those groups constantly because I found the support was fantastic you can be completely uninhibited because everyone is in a similar situation and they are always sympathetic and they don't say is he getting better?'*

A7's professional relationships varied. Within the hospital environment they were described as difficult and unsettling, due to the pressure to find a care home.

*'She went onto a long stay ward there were lots of people with end stage dementia and umm she wasn't that unwell at the time and I think that must have an effect on you I know it had an effect on me it was a very unsettling time.'*

AB moving into a care home meant that the relationships had time to settle and the burden of the practical arrangements was finally reduced. The knowledge that AB was being well cared for in a comfortable and receptive environment was very important and relieved some of the burden from A7.

*'For me one of the biggest release came when she moved into the home that she has been in now for 4 years and I knew then once she was in a home I could start to relax about her daily hands on care in a sense.'*

Relationships started to build with the care staff and manager of the home; A7 trusts that with such relationships in place, she can ask questions and that the care her mother is receiving is reliable and comforting,

*'I have a very good relationship with the manager of the home she is very open, very honest about the changing nature of my mother's illness and they have kept us up to date with any changes in medication and things like that and if there is any problem you can go to them and for me that is also a sense of relief.'*

Her concerns about AB's cultural care being recognised were alleviated by the care home building a life story book with AB and the family; this also helped to support the trusting relationship.

*'One of the things I was asked to do before she moved in was to write a little profile of her life with key things that I knew about so that when they were talking to her they would know some of the things that had happened in her life, so if she started*

*wandering off or asking for people they had an idea of what she was talking about and that impressed me.'*

A8 felt she wasn't being listened to by the professionals she came into contact with and it seemed nobody would listen to her concerns about her husband's changing behaviour and memory problems,

*'4 or 5 times the plaster is tight it is this it is that all the time he was aggressive he was shouting, screaming they took him to hospital and they did a brain scan they didn't take me seriously either it was the junior doctor who actually did a scan and when it was read I think it was read either by the senior house officer or registrar I am not sure he said everything is fine take him home.'*

It may be because of her practiced communication skills that A9 has received the support she required; for example, she made a good relationship with carer support services that provided her with one to one and group support,

*'The Admiral Nurse she had time for me we had one to one meetings for an hour this was very valuable. I had somebody to advocate and I felt safe. The Admiral Nurse was calm with an all embracing personality, could answer things, educate, was non-judgemental I trusted her.'*

She highlighted the importance of maintaining continuity of the person delivering the one to one support as her support ceased when one of the people she had built a relationship with left the service. The service was still available to her with a different person but she did not feel sufficiently confident or worthy to request it. It seems the element of continuity was very important for a trusting relationship to build up and once the person left it was difficult to begin again. Subsequent to the one to one support ceasing, A9 was found to have raised blood pressure and other symptoms of stress.

#### 4. Stabilising relationships to 'move on'

One of the most important things that A1 talked about was the importance of him giving something back. The first thing he did was return to the home where A had lived to help out

as a ‘visitor’. He found this a comfortable way of ‘giving back’. This is not to say that this was a ‘best of’ feeling but with the support of the Admiral Nurse he gradually became more involved with an ‘outside’ life again,

*‘My bedrock was the Admiral Nurse she continued to visit every month after A died.’*

After several months of one to one support A1 was introduced to further support where he could begin to value his caring role.

*‘Introduced by my Admiral Nurse 3 months after A passed away, I went to a meeting arranged by for dementia I really wanted to go, I wanted to pay something back, and I said I would like to help. This group is now Uniting Carers for dementia..... I also love talking to students training is very important the staff at A’s care home were trained it made such a difference. I talk about brain donation (A’s brain was donated) and my experiences.’*

A1 now leads a very active life involved in various voluntary organisations and enjoys frequent travelling.

A3’s description of development of relationships was focused on giving back to his father. He explained how he strives to provide the ‘best of’ for him whilst balancing his own relationships with his daughter and wife. He has included others in the relationships who understand his father and in some incidences has bridged a previous relationship with his insightful and practical interventions.

*‘One of the things which I would dearly love to have a bit more time early on my dad is absolutely mad about railways he lived on the railway out of Euston. As a school boy he was probably one of the first train spotters.’*

He also highlighted that development of a relationship requires mutuality and described briefly the difficulties with his relationship with his brother, who lives in Australia.

*‘I mean we have an agreement that we negotiate I don’t want to go into all of that, where we will share the load the reality of that is .....it is an opportunity for him to get out of the winter..... If my brother would take him for 4 months over the winter it would be a great help from my part quite a lot has gone into it.’*

The concerns about his father going to Australia were voiced within the relationship he has with his brother. The feeling that his brother should be giving something to the relationship with his father and himself was very strong. ‘Dad’ has visited Australia for the last 3 years for an 8 week period over New Year until the end of February. This provides a period of respite for A3 and his family and gets his father away during the worst of the cold winter months. A3 acknowledges that this will not be able to continue long-term but raised concerns at his brother’s lack of understanding about the importance of maintaining the relationships whilst they can.

A4 explains that communicating with L does not necessarily mean talking to him. She describes below that their relationship has developed so that she feels rested and safe if she sits comfortably beside him. By resting in another room she would feel anxious about his wellbeing thus encroaching on her own rest time. She has been urged by professionals to take up the offer of help from services but the intrusion into her personal space and relationship she has transformed with L prevents her from taking this step or ‘moving on’.

*‘sometimes when I am very, very tired I just close my eyes I usually sit in his room if we didn’t sit together then I would be worried .....’*

A5 described how she prefers to be able to complete the practical and day to day tasks for her mother herself. She has, however, realised that the relationships in her own life are important and require development to be able to take on a caring role. A5 expressed that she finds it hard to value herself and always puts others first. A5 is finding it difficult to identify herself as a person. To move on with these feelings she may need help.

Following P’s death A6 has continued to keep in touch with the organisation she attended the groups through. Now, her role has changed and she speaks to the groups as part of the

training team. She has made lasting friendships and found that her confidence and leadership skills have improved since before she cared for P.

*'I do a carers group when they are training carers and one of the things they ask is was their anything positive and what came out of it was I developed lasting friendships and also it changed my personality because I was always very introvert I would never speak out but now not only can I speak in a room full of people but I can speak in front of perhaps 20 people who are in a training session to answer their questions which I could never have done before that is rewarding and satisfying.'*

A7 talked about the importance of giving something back. She did not describe how or why she felt this was necessary just that they have joined a research study at the hospital.

*'We are also part as a way of sort of contributing back or I feel very strongly about giving back for some of the care my mum has received ummm our Admiral Nurse ummm put us in touch with a team at the Hospital who are carrying out a long-term study of dementia.'*

At the time of interview A8 was feeling very low she had been unwell herself as well as coping with the traumatic events of her husband's care. The relationships that had showed most development for her were within her family and with close friends. These relationships were without judgment or burden. She trusted her family and friends to communicate with her and her husband and act as 'bridge' between them.

Following her admission into a care home, A8's mother has developed a trusting relationship with the matron and care staff. The continuity of the same staff had enabled her to feel that she is working in partnership with them. Her son feels relaxed within the environment and able to continue his relationship as grandson with his grandmother.

## **Summary**

The lives and experiences of each of the carers varied enormously. Significantly, the differences that were the very essence of their individuality were threatened by their caring

role. They are now labelled as carer, thereby limiting the way that they can express their personhood. They place themselves in the centre of managing the support systems for the person with dementia, drawing on: personal experiences; coping strategies; knowledge; skills and support from professionals. Previous research has drawn on this (see Chapter 2) highlighting the physical and emotional burden that can become a reason for carer crisis and subsequent admission for the person with dementia. The findings from this stage show that by using strategies to ‘stabilise’ the relationships they are involved in, carers can find a plateau for an unspecified amount of time of value and wellbeing within their caring role.

The next section of this chapter describes the data collection in the second phase of the discovery stage of the 4 ‘D’ cycle. The data collection continues with a group of carers, people with dementia, Admiral Nurses and stakeholders to inquire into the value of the Admiral Nurse.

## **Focus Groups**

Collecting data in the carer, people with dementia, Admiral Nurse and stakeholder strand (2) of the study was a far less emotive experience for me as a researcher as it was a more formal process that was easy to set within the appreciative inquiry methodology. This formality was due to the larger number of participants which in turn gave rise to the relationships between the participants and myself being less intensive as participants were supported by each other and relying less on me.

Focus group 1 was designed to build on the positive core of what carers, people with dementia, stakeholders and Admiral Nurses ‘value’ about the Admiral Nurse. Each potential participant was contacted either by letter or email with the study information sheet and a

consent form as attachments. Questions and queries were invited and I gave contact details and information when I could speak to people or visit them.

### ***Pre-Group Contact***

The carers and people with dementia attended two distinct groups in the South East of England. These groups were chosen for my ease of access as I work and practice in the area. The facilitators of the groups had been contacted during the ethical approval process to ascertain if it would be appropriate to ask the participants of their groups to be invited to join the study. Both groups were designed to create time when both carers and people with dementia can come together for a social morning/support, information and advice based on the design of the Alzheimer's Café (Meisen and Jones 2004; Capus 2005). The facilitators of the group distributed the study information and consent forms on my behalf and I arranged a 'pre-study visit' to the first group. My visit was well received and I found people interested and buoyant about being part of a research study. I introduced a warm up exercise to give people an idea of what it would be like to participate; this induced lively and memorable conversations. I placed a selection of pictures saved from post cards and greetings cards on a table and asked each person to pick one that they could say something about with a positive focus for example its texture, colour, a memory. The written consent process for the study was left for people to think about and they were able to return their form to the facilitator at the next meeting. The facilitator of the second group declined the pre study visit as the programme for the group was heavily booked.

My reflective notes highlight how the pre-study visit made a memorable connection with the group and when I returned, the atmosphere felt relaxed and welcoming. People were ready to engage and had few questions to ask. This left me more time to speak to the people with dementia explaining the reason for my visit and checking that they still felt comfortable with

participating in the study. One man (who had dementia) particularly remembered me when I arrived and delightedly made me a cup of tea and greeted me with enthusiasm. He was keen to participate with his wife and couldn't wait to tell me what his 'values' were. Another lady with dementia was new to the group and asked if she could join in. I was able to spend some time talking to her about the study and give her time to decide if she would like to give written consent. She subsequently joined in the group. The second group was much larger and in an area where I had been a practicing Admiral Nurse some 4 years before. I had not prepared myself for the overwhelming welcome from some of my past carers and family members. Some people had attended the group that day especially to be part of the research.

The Admiral Nurse groups were facilitated in designated monthly practice development time. Each practice development group was contacted in advance to book a convenient date and time for me to attend. Nurses who did not want to participate were then able to arrange alternative practice development learning, reading or reflection time. Attending the groups necessitated travelling around the UK to each of the practice development areas making careful booking essential to maintain time management of the study.

The stakeholders group was held at an Admiral Nurse Forum. The forums are twice yearly meetings for Admiral Nurses, carers and stakeholders and are designed to support practice and future service development. A large number of stakeholders attend the forum making it an ideal opportunity to get a group of people together. The group was available during workshop time and ran twice during the day, allowing people to attend their chosen workshops as well as the group. Running the group during the forum also reduced travelling time, cost and administrative resources. Information sheets about the study and consent forms were sent by email to stakeholders before the forum and were available on the day in paper

form. A cross section of stakeholders volunteered to participate including: trustees of *for dementia*; service managers; administrators; members of Uniting Carers *for dementia* and executive staff. A total of 11 groups with 93 participants were facilitated in different areas of England from 04/01/08 – 07/03/08.

### ***Facilitating the focus groups***

To provide continuity and reduce bias, all the groups were facilitated using the same process. After introducing myself and checking all the participants were attending on a voluntary basis I checked the signed consent form for each participant. This was a lengthy process in some groups as they exceeded the preferred 8 - 12 participants (Robson 2002).

Each group was provided with a disposable table cloth and a selection of fibre tipped pens. I asked each group to volunteer a note taker. This worked well in the groups of Admiral Nurses and stakeholders but proved to be difficult in the carer and people with dementia group where no one volunteered. I feel this was due to my naivety of thinking that everyone would feel at ease in a group environment. However, making the request actually increased anxiety about writing and ‘doing it right’. I found that by sitting with the group it helped support feelings of anxiety and worry about being ‘right’ as I was able to use positive prompts and ask people questions to help them illustrate or write what they were thinking.

The question ‘What is valued about Admiral Nursing?’ was either available to see using power point or on a print out/flip chart. This depended on the venue, its available resources and the needs of the participants. I recognised that the people with dementia who participated may need support to fully take part. Most people sat with their carer and in cases where they were not accompanied I sat nearby offering help as appropriate.

Each of the groups undertook the mind mapping of ‘value’ in a different way. Some groups divided the map into distinct areas of value and others drew a diagram or picture. A lot of the discussion included a ‘story’ behind the value, either of a practice example or a real life experience. After each group a reflective piece was written about the experience. All the groups found the mind map exercise a productive and valuable way of developing a discussion. I found it a comfortable non threatening way of including participants with a wide range of knowledge, experience and skills.

After observing focus group 1 (04/01/08) I could see an emerging pattern of connected ‘relationships’ in the value of the Admiral Nurse. Below is a description of the four ‘stabilising relationships’ that began to emerge from the groups:

1. The Admiral Nurse and the person with dementia.
2. The Admiral Nurse and the carer.
3. The Admiral Nurse and other professionals.
4. The Admiral Nurse skills and knowledge

The groups are not distinctive as the values overlap but show an emerging theory of holistic relationship building.

### ***The Admiral Nurse and Person with Dementia***

In focus group 7 on 22/02/08 a gentleman with dementia drew a picture. He was able to talk about what he valued about the Admiral Nurse through his sketches, describing his feelings as comfortable and showing he is not being made to feel different or awkward as he often is in other settings. The illustration of the tea pot and first a cup that developed into a ‘cup cake’ denotes the sociability that is important to him and the feeling he can talk freely without feelings of stigma or assumptions about having a diagnosis of dementia (appendix 10). His

contribution led to his wife joining in with a game of noughts and crosses and a conversation about having time to enjoy each other's company without judgment, being able to talk about dementia and learn about it and other associated things on a 'need to know basis'. In focus group, 8 07/03/08, a lady with dementia talked about the importance of feeling included,

*'the Admiral Nurse keeps him sane, help support each other, to do good things together, is back up and who else would you talk to?'*

The relationship between this lady and the Admiral Nurse had been built in this context during a social group meeting that she and her husband attended as a couple each week. The relationship with her husband is clearly important and the ability to do things together a necessary part of their life together.

### ***The Admiral Nurse and Carer***

The relationship between the Admiral Nurse and the carer was valued for its continuity, allowing the relationship to develop over a period of time. The time allowed was valued as it was agreed in partnership with the carer and could include time alone with the Admiral Nurse. In focus group 1, 04/01/08, the group used the analogy of a light house by placing the Admiral Nurse as the 'light at the end of the tunnel' achieved by using knowledge and understanding of a caring role of a person with dementia to support the carer. The analogy was underpinned by the 'rock' of the lighthouse, visualising the Admiral Nurse as reliable, trustworthy and honest. Someone who was always there to guide a carer "through rough sea" working in partnership to empower the carer to build relationships with others; for example: professionals, family members and friends (appendix 11). In focus group 2, 04/01/08, the participants emphasised the relationship between the Admiral Nurse and carer as working at the same level: warmth, linking with family members and being a friend. The participants also highlighted the importance of accessibility; being able to contact an Admiral Nurse

without going through another person or agency supported the building of the nurse relationship.

The following quote from my field notes taken by note taker focus group 3, 07/01/08 summarises this,

*'Admiral Nurses have knowledge and skills, are flexible, carers can dip in and out of the service, (we) Admiral Nurses are non-judgmental, a resource for information and sign posting. Relationship building, being 'real', honest and solution focused builds trust, answers questions and doubts.'*

This way of connecting with a carer, in turn, made the carer feel valued and less isolated. The relationship was frequently referred to as a friendship which caused concern for some participants. Friendship is not necessarily seen as a professional relationship but is a frequently used term of discourse throughout the data in this thesis. Discussions about friendship developed into discussing dependency with Admiral Nurses viewing dependency as something to avoid in the climate of national and local policy and the local pressures of measuring frequency of face to face contact. The value the carers and people with dementia held was the 'timeless' nature of the Admiral Nurse relationship relating it to in terms of friendship.

From field notes taken by note taker focus group 1 on 04/01/08,

*'Friends, professionals, friendship – is this the depth of the therapeutic relationship, there is disclosure of some personal life events and sharing of emotions and loosening of boundaries, is this professional 'with heart'? Carers value in out even after death of the person with dementia honesty comes from a therapeutic role are we afraid to use friend?'*

and field notes taken focus group 2 on 04/01/08,

*'friendship/relationship with the carer is important carers feel we are (at) their level.'*

It is interesting to note that some of the carer's relationships were maintained within a group setting, not face to face; with telephone backup should the carer wish to contact the Admiral

Nurse between groups. Carers still considered the contact they had with the Admiral Nurse as a ‘friendship’. It is possible at this stage to theorise that the interpretation of friendship is made because of the flexibility and accessibility of the Admiral Nurse. It is much the same as having access to a friend who you could rely on to get back to you and give advice and comfort at a time of need. One participant told of carers phoning into listen to the answer machine message as the sound of the voice of the Admiral Nurse was a comfort and they could ‘speak’ to them knowing the conversation would be heard and replied to at a given time in the future. Other stories recounted messages being exchanged on email. There does not necessarily appear to be a need for the Admiral Nurse to offer face to face contact with every carer to be valued in practice.

The Admiral Nurse is valued for his/her holistic approach as illustrated from an excerpt from field notes taken by note taker focus group 2 on 04/01/08:

*‘The Admiral Nurse works with tasks no other professional would be involved in, supporting the carers when no other professional will help, using advocacy, working in partnership and empowering carers.’*

This was further articulated in focus group 8 07/03/08 by a carer,

*‘Someone who understands how it is for you, and not how it should be.’*

Admiral Nurses supporting carers after the death of the person with dementia was highly valued by participants. Admiral Nurses found it an important value of their work to fully support feelings of loss and grief and carers found the ongoing relationship helped them engage and develop in new relationships. Discussions about how national and local policies are impacting on the Admiral Nurse developing relationships with the carer were heated and the feelings of participants were resounding in that the continuing relationship should be part of a clinical partnership between carer and Admiral Nurse. From field notes taken by note taker focus group 10 on 28/02/08,

*'the Admiral Nurse provides continuity from pre-diagnosis to after death with the support of other agencies.'*

### ***The Admiral Nurse and other Professionals***

The relationship the Admiral Nurse has with health and social care colleagues was also highly valued. Working collaboratively was highlighted as integral to Admiral Nurse practice; for example, relieving carers of practical and financial burdens quickly and efficiently were frequent. Other stories recounted how contact with an Admiral Nurse had empowered carers to develop new relationships with other services and care home staff in particular. This is illustrated from field notes taken by the note taker in focus group 1 on 04/01/08,

*'Sharing ideas and experiences to fit other people's needs. Communication at all levels we work in under resourced areas but are creative and 'cunning' in how we use resources and pull services together.'*

and from focus group 10 on 28/02/08,

*'the Admiral Nurse bridges 'tensions' between medical and the social model of dementia care.' and "working with an Admiral Nurse supports other services, referrals have become appropriate since the Admiral Nurse has joined the team.'*

A further value to other professionals was for their consultancy and training role, from note taker focus group 9 on 28/01/08.

*'the consultancy role is valued when the service is receiving inappropriate referrals we can signpost, guide and inform our colleagues.'*

Working with an Admiral Nurse within a team was widely valued; it was recognised how Admiral Nurses reciprocate value based working. Focus group 9 on 28/01/08 continued,

*'.... one that takes into consideration the needs of individual communities, one that includes the whole family, one that listens to carers!'*

Although leadership was not named as a value it was articulated using the terms,

*'striving for excellence' and "striving for excellence .... responsive and flexible.'*

(Focus group 11 28/01/08)

The Admiral Nurse was valued for his/her attitude towards working with others, this included working across organisations and enabling carers to work with organisations and other professionals as well; carers articulated this as 'feeling safe'.

As already discussed in Chapter 3, Mitchell (2005) advocates a whole team approach to family-centred approaches to children's care. The value of working with an Admiral Nurse is clearly an emerging theme in this discovery stage of the 4 'D' cycle. It clearly overlaps with the level of knowledge and expertise of the Admiral Nurse and includes personal attributes which, as previously stated, cross all four of the relationships contexts.

### ***Admiral Nurse Skills and Knowledge***

Admiral Nurses' skills and knowledge featured as highly valued but, interestingly, were not defined in other words or language. This became largely entwined with values identified as personal attributes of the Admiral Nurse by focus group 5 on 17/01/08. This group divided their tablecloth into four sections: the person with dementia (1), the carer (2), the Admiral Nurse (3) and our colleagues (4). The attributes included: value of flexibility, being accessible (even though this often involved creativity on part of the Admiral Nurse), going 'the extra mile', warmth and embracing (appendix 12). These values were not identified in isolation and were a constant across all 11 focus groups. Knowledge, skills and specialism was also a constant across all the groups. These values again linked across the relationship context; group 3 on 07/01/08 discussed the importance of knowledge and skills from the point of view of competence and professional development of the Admiral Nurse agreeing with other groups that the opportunity of regular peer group supervision and practice development was a value. From field notes taken by note taker focus group 3 on 07/01/08,

*'updating of knowledge can be addressed via supervision and practice development.'*

Focus group 4 on 17/01/08 validated this when discussing the value of practice development and supervision, identifying how fellow practitioners value the Admiral Nurses' continuing professional development,

*'we are often requested to be clinical supervisors.'*

People with dementia and carers highly valued the Admiral Nurses' skills and knowledge about how to give information, whether practical or evidence based. The way the Admiral Nurse was able to communicate and share information at various levels and across a range of organisations to meet individual needs was valued. For many the Admiral Nurse was the only person they could talk to about having dementia or about the facts of what dementia was, including changing symptoms. In focus group 8 on 07/03/08 a carer said,

*'people are frightened of dementia, here we talk about having dementia, feel safe have fun and a laugh.'*

Admiral Nurses' knowledge and skills were also valued for the training and/or education they facilitate. Delivering training and education involved skills valued by people with dementia and carers; for example, listening and empathy. These skills were valued highly, indicating that Admiral Nurses have the ability to manage complex situations that involve working across boundaries within health, social care and voluntary services. The Admiral Nurse was articulated as a leader and manager in complex circumstances who could empower and work effectively in partnership. However, these values did hold tensions; promoting discussions about decision making and appropriateness of signposting and discharging a carer due to service provision constraints. The value of group supervision and practice development were highlighted here as a way of supporting the decisions made by the Admiral Nurse but the frustrations of continually striving for the ideal were voiced (focus group 3 on 17/01/08 and focus group 4 on 28/01/08).

The mind maps were initially read through and written up entering the data onto Nvivo7. The data were then coded into the 40 values of Admiral Nursing (table 7). The values were then sent by email and post to the reference group for comment. Suggestions around classification were made; for example, using four headings: function (1); professional (2); personal (3) and organisational (4) (reference group member JM via email 21/02/08). These headings were compared with my own headings and collapsed into four headings to offer with the 40 values to the focus groups in the dream stage of the 4 'D' cycle:

1. Organisations and partnerships
2. Admiral Nurse attributes and qualities
3. Meeting the needs of the carer and person with dementia
4. Admiral Nurse clinical skills

The principles and values are further developed and constructed with the participants in the dreams stage of the 4 'D' cycle.

**Table 6**                   **Admiral Nurse Values**

<b>Admiral Nurse Values</b> <ul style="list-style-type: none"> <li>working across organisational boundaries</li> <li>meeting the needs of the carer</li> <li>attitudes</li> <li>supporting relationships</li> <li>flexibility</li> <li>communication</li> <li>partnership</li> <li>working with people with dementia</li> <li>accessibility</li> <li>sharing</li> <li>trust</li> <li>collaborative working</li> <li>knowledge</li> <li>consultancy</li> <li>for dementia</li> <li>working with families</li> <li>meeting mental health needs of the carer</li> <li>information</li> <li>specialism</li> <li>honesty</li> <li>continuity</li> </ul>	<ul style="list-style-type: none"> <li>person centred</li> <li>therapeutic interventions</li> <li>empathy</li> <li>nurse led</li> <li>meaningful activities</li> <li>skills</li> <li>quality of service</li> <li>commitment of Admiral Nurse</li> <li>practice development</li> <li>autonomy</li> <li>support</li> <li>peer group supervision</li> <li>empowering</li> <li>friendship</li> <li>practical help</li> <li>record keeping</li> <li>physical needs</li> <li>responsive</li> <li>gold standard service</li> </ul>
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## **6.2 Dream - continuing the appreciative inquiry 4 ‘D’ cycle**

*‘This is a picture of tenderness and I like that. It represents the best and most immediate means of communication left to us – touch.’*  
(Carer A4 photograph and narrative 3/6)

Once the ‘positive core’ has been established the next stage in appreciative inquiry is to envision the future. The dream stage of the 4 ‘D’ cycle aims to accomplish this. The dream stage is an invitation to participants to magnify the positive core by imagining and building on the existing values generated in the discovery stage. Participants are encouraged to talk about (and dream about), not what is but what might be a better ‘world’ (Cooperrider *et. al.* 2005). The dream stage has two aims. Firstly, to facilitate dialogue between participants in which they can share positive stories in a way that generates enthusiasm and energy. This is accomplished by asking the participants of the discovery stage to further build upon and share their stories and discussions with others. The stories and content of the discussions are the vehicles for bringing out the positive core, therefore those sharing stories and discussions must be encouraged to develop the essence of their stories. The second aim of the dream stage is to allow the participants to start to identify common themes. It is important to encourage the groups to observe and value the dialogues in the phase rather than critique, judge or analyse them. It was important to emphasise the appreciative inquiry themes of not solving a problem but focusing on the journey of mutual discovery rather than an analytical journey. The positive themes then become the building blocks for the design stage of the appreciative inquiry process (Reed 2007).

The dream stage of the 4 ‘D’ cycle begins with a description of the process of collecting the photographs and narratives and a co-construction of the data collected in the telephone

interviews. The later part of this section is a description of the second round of focus groups using an adapted version of the nominal group technique. The chapter concludes with a co construction of the data collected so far and preparations to move the findings into the design stage of the appreciative inquiry cycle.

### **Collecting Data in the Dream Stage**

Reflecting on how participants had interacted and contributed in the focus groups as part of the discovery stage, I decided to change the method of data collection to allow those who had not contributed in focus group 1 to have a voice. I had noted in several entries in my reflective diary that a number of participants had remained silent in the focus groups. This could have been due to several reasons, such as feeling challenged about individual practice, feeling intimidated or not feeling confident speaking in a peer group. I also reflected on the use of mind mapping and considered its use being interpreted as being vague and too artistically creative to be of worth. It is interesting however that this did not arise in the carer and people with dementia groups. In these groups everyone engaged, participating and supporting each other and making sure each person had the opportunity to have an equal voice. Nominal group technique was considered and developed for the dream stage with adjustments being made to enable all the participants to be included in the stage.

It was also important to continue the co-construction of the themes and investigate the underlying relationships that the data developed from the telephone interviews. The use of photography and narrative was chosen to give control of the data collection to the carers. Guidance and support were available throughout the whole of the stage by way of me making myself available through telephone or email contact at organised times of the day and week. The co- construction of the data of the discovery stage identified and started to develop the value of how carer relationships develop and are maintained and stabilised throughout and

beyond a caring role. The dream stage of appreciative inquiry is designed to develop the common themes and acknowledge the possibility of ‘greatness’ identifying a positive core and a creative way of maintaining the spirit of the appreciative inquiry methodology. The use of visual methodology and narrative was for me a logical way to develop the stories heard in the telephone interviews, possibly giving an easier medium for the participants to articulate difficult to identify emotions, knowledge and skills.

### ***Photography with narrative***

To begin the process of collecting visual data it was important for each participant to view and read a transcript of their telephone interview to agree the content and view the identified themes of their story. Written consent had been obtained for each participant at the beginning of the discovery stage; each carer was reminded of this before embarking on the dream stage. All 9 carers participated in this stage over a period of 8 months. The participant who had declined to participate in the telephone interviews contacted me to say she was feeling much better after a visit to her family and would like to participate for the remainder of the study (she was aware of this stage commencing as I had kept her informed of the progress of the study through the *for dementia* co-ordinator of Uniting Carers *for dementia*). An event of this nature had been built into the study design and was not a problem. Written consent was obtained from the participant before she stepped onto the study. As this person had not taken part in the telephone interviews, she was asked during an informal telephone conversation to think about times, events and environments that had contributed to feelings of value and well-being and skills she had used or developed whilst she had been caring in preparation to join the stage. The telephone transcripts were sent either via email or by post with a pre paid envelope for return to me to the remaining 8 participants. Each carer agreed with the

identified themes only making changes to some personal health references or reference to family members or friends.

Guidance notes were then sent out with a disposable camera with 27 photographs to each participant (appendix 13). Particular attention was given to what the main body of the photograph should contain due to restrictions in ethical approval for example; taking pictures of people who had not consented to participate in the research, or of people with dementia who were unable to give consent due to cognitive decline. It was only the participant who had consented to be part of the research who could appear in the photo.

A pre paid envelope and date for return were enclosed with each camera with details of when and where I was available to support the process. On receipt of all the cameras they were taken for developing. Two copies of the prints were obtained with a copy of each film onto CD for ease of use during the data analysis. Two participants chose to use their own digital camera and email 6 chosen pictures to me. Each participant's photographs were numbered to reduce the need to 'swap' photos in the future. A complete set of prints was then returned to each participant. They were asked to choose 6 photographs and write a narrative to describe feelings of wellbeing and/or how the picture illustrated skills they had used. A pre paid envelope was included for the return of the narratives. Some participants had included pictures of family members and/or pictures of the person they care for and staff members. They were gently reminded that these pictures would not be able to be used in the final write up of the thesis. However, some did choose this type of picture as one of their chosen pictures. They have been used in the overall co construction of the data but do not appear here or have been edited to maintain confidentiality and to adhere to ethical approval. To maintain the emotional voice of each carer as many of the chosen pictures and narratives as

possible are included in appendix 14. Each carer carries the same code as in the discovery stage, enabling links to be made in the comparison of the data.

By comparing the data collected in the discovery stage with the photography and narratives from each of the 9 carers, stability of the carers relationships was further developed and is described here using the same four headings as in the discovery stage: stabilising the relationship between the carer and person with dementia (1), stabilising family relationships (2), professional relationships that stabilise (3), stabilising relationships to ‘move on’ (4).

### ***1. Stabilising the relationship between the carer and the person with dementia***

A1 described in the discovery stage how lonely he felt when his wife was no longer able to be part of the decision making process that he had enjoyed sharing throughout their married life. An overview of his pictures and narrative (A1 1/6 – 6/6) builds on his description of love and devotion to A which is now held in his memory by distinctive objects in the house and places where they shared happy memories and now have lasting meaning. He revisits the importance of A’s cultural background and her spiritual wellbeing by referring to the ornaments in pictures A1 5/6 and 6/6 as important now to his feelings of wellbeing.

Carer A2 did not participate in the telephone interviews but felt well enough to contribute photographs and narratives. Her relationship with her husband is described though photographs A2 2/6 and 6/6. In these photographs she is remembering the feelings of wellbeing when listening to favourite pieces of music and reminiscing about her husband’s status as a councillor. The mirror is a reminder of how she found a strategy to keep her husband’s attention whilst she helped him with personal care. Photograph A2 6/6 has two distinctive memories, a memory of when her husband was well and their relationship as husband and wife and a later memory of when he used to attend the day care facility run by

the Cypriot Elderly. At this point in her caring role her relationship with her husband had changed.

A3's relationship with his father differs from that of A1 and A2 as it became closer with the onset of his father's Alzheimer's disease. The photographs and narratives A3 1/6 – 6/6 show a series of relationship focused examples. The most poignant being 1/6, 2/6 and 5/6, illustrating their close relationship and the ability of A3 to communicate with his father about his likes and dislikes, as well as including him in meaningful day to day activities. The photographs and narrative substantially validate his telephone interview transcript.

A5 further substantiates these feelings with her illustrations of the things her mother likes: A5 1/6; 4/6; 5/6 and 6/6. A5 3/6 shows a practical intervention aimed at resolving mobility problems so that she can still enjoy going out with her mother. In her interview A5 talked about going on holiday and how the relationship with her mother was natural and normal. Her photographs show techniques and strategies that she has implemented to support the

Carer A6 talked of the struggle she had in maintaining her relationship with her husband P in her interview. Her photographs and narrative illustrate and further validate her feelings and the relationship she maintained with P (photograph and narrative: A6 3/6; 4/6; 5/6 and 6/6). Some of the interventions she found, such as the fish finger, seem to be so simple but had an enormous impact on her feelings of wellbeing.

A7 photograph and narrative 5/6 movingly describes how sensory stimulation can evoke feelings of wellbeing when she describes the smell of her mother's talc and perfume. These evoke memories of before she had dementia but at the same time also currently seem to support her feelings of wellbeing now that she has found a care home where she is well cared

for. The relationship has become more relaxed and feelings of wellbeing translate between them as described in photograph and narrative 2/6. A4 photograph and narrative 4/6 movingly shows the close relationship she retains with L. She uses her sense of spirituality as her way of expressing their close relationship and feelings of wellbeing and tenderness. She has managed to retain their privacy by organising services that suit her needs so that she can find this window of closeness on a regular basis. This set of photographs and narratives validate the relationships between the carer and the person with dementia. The relationship is uncovered, finally, from the distress and burden of care through this pictorial dialogue; providing a moving insight into the life of a carer for a person with dementia.

## ***2. Stabilising family relationships***

The comparison of the telephone data highlighted shifts and changes in family relationships. A3 photograph and narrative 3/6, 4/6 and 6/6 show his father joining in everyday activities with his family. He strove to keep the relationships as ‘family relationships’ by involving his father in meaningful activities each weekend. Being able to join in and achieve gave his father a sense of belonging and achievement which was very important to A3. Carer A2 photograph and narrative 5/6 illustrates a memory of family time together in a restaurant. Previously A2 had talked about her sadness at many friends and family members disappearing as P’s dementia progressed; however, taking the picture and writing the narrative had reminded her of the feelings of wellbeing when they were all together. A4 has found different ways to connect with family life (photograph and narrative A4 5/6). She misses seeing her family as often as she would choose because of her caring commitments but has found a way to connect with the family living opposite: photograph and narrative A4 1/6. A7 recounted her distress when her daughter visited her mother in hospital, breaking down a close granddaughter/grandmother relationship. She illustrates in photograph A7 2/6 how the relationship was allowed to recover once her mother was admitted to a care home.

Her daughter is now involved with her grandmother's care and the relationship has been reconstructed. A8 has an experience that has been harrowing; she recounts the way that her family are the centre of her life and illustrates this in her photographs: A8 2/6 and 3/6.

### *3. Professional relationships that stabilise*

It was disappointing to find in the telephone interviews that professional relationships caused the 8 participating carers so much distress. Sadly the picture I painted in my reflexive account (Chapter 1) still exists in many guises in today's dementia care practice. In some ways the distress caused by inflexible and inaccessible services is hidden beneath a wealth of well intentioned information and a mire of health, social and voluntary services all of which are not provided equitably across the United Kingdom (DH 2009). The stories that A1; A6; A7 and A9 recounted are of anguish about choosing the right care home and the struggle they had caring before the admission. This changed with the relief of finding, the right place and being able to build relationships with the care home staff. Carer A1 validates the importance he placed on cultural sensitivity; when looking for a placement for his wife he chose to photograph meaningful objects that symbolise his wife's cultural heritage. Carer A7 talked of her distress in the interim of finding her mother a placement that she felt was right for her, with her photograph and narrative A7 1/6. Here she further describes her relief of finding somewhere that cares for her mother with respect so that she can transform the relationships she has with her daughter and her husband.

A8's experience is, however, different; she had suffered great distress whilst trying to gain a diagnosis for her husband and this has impacted on her own health so she has not been able to make the choice about caring for her husband at home. She remains in great distress and illustrated this in the photographs she took of her husband in the care home photograph and narrative A8 5/6. To transform the relationship she has with the staff, she is building

confidence in the care her husband is receiving, she has observed elements that have increased her sense of wellbeing as illustrated in photograph and narrative A8 6/6. Although I interpreted this as a particularly sad photograph of her husband sitting with his head in his hands alone in the lounge area, her narrative disputes my assumption. Their relationship has been fractured by her husband being cared for away from the family home and she is now receiving help to stabilise this, again from the Admiral Nurse with whom she has a trusting relationship.

#### *4. Stabilising to ‘move on’*

A2 shares with us the open door of her home illustrating how ‘people come and go’ from it (photograph and narrative A2 1/6). Later in her series of photographs she shows the builder who became part of their lives during her husband’s dementia. The building work was not just about making their home comfortable but also valued for the development of the relationship they built with the builder who was very patient and became a friend. In her photograph and narrative 3/6 A2 shows the value she places on her pet cats stating simply that they were usually with them. This is a reminder that new relationships are not necessarily with humans and that pets can play a large part in people’s lives.

Carer A4 became quite distressed during the telephone interview, as she felt services were intruding in her home and the intimate relationship she shared. However, by further exploring this with the photographs she found that their intimate relationship was intact and movingly illustrates this in photograph and narrative A4 4/6 and 5/6. The difficulty highlighted by the carers in the discovery stage was the distress that is manifested in managing the shifts and changes when they feel they have no control. Carer A5 illustrates this with her set of pictures A5 1/6 – 6/6 she has chosen practical scenarios that validate her telephone interview about having a ‘normal’ relationship with her mother. Each of the interventions she has chosen to

photograph underpins the way she continues to support and nurture the relationship she has with her mother. A6 validates this when talking about the comfort she found in developing relationships with the care home staff (photograph and narrative A6 1/6). Her relationship with P had already changed out of all recognition (as described in her telephone interview) but once he was living in the care home she was able to find short periods when she could engage with him in a comfortable way (photograph and narrative A6 2/6), this was development of a different relationship from when he was living at home where her caring role had become stressful and chaotic.

Finally A7 described how her relationships developed with the care home staff. She became involved with fundraising as this was a way she could engage her daughter with her grandmother again (photograph and narrative A7 2/6). The photograph and narrative she has written support her feelings of peace and tranquillity and the feelings of wellbeing she has when her daughter can be involved in her grandmother's care. She has found a space in which her relationship with her mother has developed and is now less anxiety provoking. A9 photographs and narratives 1/6 – 6/6 support A7's feelings of wellbeing with the new relationships that have developed since the beginning of their caring role. As A8 previously discussed, she has experienced different feelings in trying to develop new relationships. Her traumatic experience with various professionals has left her feeling sad and lonely and now physically unwell. A8 has a developing relationship with an Admiral Nurse and is relying heavily on her family relationships for some stability during this difficult time. She depicts these times in her photographs and narratives A4 5/6, her pictures show members of their family as they cluster close to her husband, unlike the picture A8 4/6 that shows A8's husband totally alone in a dining room hunched over a plate of food. Developing new relationships, therefore, is not always a positive experience or a development the carer is

ready to embrace. A period of stabilisation is required for this process to move the carer into a feeling of wellbeing.

## **Summary**

As the findings in this section show, the co-construction of the carers' photographs and narratives shows the way that each carer stabilises their 'caring relationships'. This is not surprising as we all 'live' with relationships in our day to day lives, finding coping strategies to manage the inevitable changes in our lives. What is unique to this study is the identification of the 4 relationship themes that concern the way that relationships are supported during a caring role to provide a period of stabilisation. The evidence indicates that the carers use many different coping strategies, drawing on their past experience and knowledge to influence stabilisation. The strategies they use promote the wellbeing of the person with dementia and include their wider family members. In situations where they are unable to use their strategies they seek help and support from a variety of professionals. However, the support they receive varies. In some instances the carer's needs are met and requests for help and support acted upon. However, in many cases the findings of this study indicate that professionals are often unaware of the emotional needs of a carer. In these instances the wellbeing of the carer is not supported.

The second strand of the inquiry in this stage ran concurrently with the carers' data collection and is described below. Carers, people with dementia, Admiral Nurse and stakeholders were invited to attend a further focus group to identify and develop the principles and values of the Admiral Nurse.

## **Focus Groups**

Focus group 2 began in March 2008, overlapping with the collection of photographs and narratives in the carers group. There were 6 focus groups with a total of 60 participants and an additional 3 responses from stakeholders. Participants were contacted either via their carers' group, practice development nurse or via email. There was no convenient way of bringing stakeholders together as a group for this part of the study. They were, therefore, contacted on an individual basis and invited to participate via email or telephone with an information sheet about the group. Each group of participants was reminded about the nature of the research before starting the group and written consent was checked. In some groups new participants had joined. In these cases I made sure-by speaking to each person privately and discretely before the group started-that they were happy with the context of their involvement and was attending in a voluntary capacity.

Each participant was given a copy of the 'Admiral Nurse Values', developed from the discovery stage. Each group lasted for an hour and the room was set up with seating and tables for small groups of no more than 10 people. Post it notes, fibre pens and paper were available on each table. Participants were asked to read through the 'values list' and note down anything they wished to comment on. Participants were then asked to co-construct the values into four headings. The title of the headings was initially the choice of the group and any number of values could be placed with each heading. Using an appreciative inquiry approach, values could also cross different headings.

The evaluation concluded that it was over complicated and that it was difficult to develop the values into headings in the hour given for the group. For this reason I adapted the use of nominal group technique (Delbecq 1986). The process of nominal group technique confused

the participants and they entered into a discussion on analysis of the values rather than further developing and building on the ‘positive core’ it was therefore necessary to adapt the nominal group technique (Reed 2007). There was also a lot of writing involved and on reflection I decided to make up sets of ‘values’. Each of the 40 values was written onto a single piece of paper in large bold font, one set made for two people. This was to ensure that people could work together and that people with dementia would always be working with someone should they require assistance. By using the following headings: Admiral Nurse clinical skills (1), Meeting the needs of the carer and person with dementia (2), Admiral Nurse qualities and attributes (3) and Organisations and partnerships (4), participants could more easily understand how to develop the values. The values (blank ‘post its’ were available for written comments or duplicate ‘values’) were then physically placed under each of the headings, thus simplifying the process and making it easier to facilitate. Each heading was placed onto a sheet of flip chart paper and the participants given ‘pritt sticks’ to adhere the values to their chosen headings. Participants in each group then developed the values into themes under each heading; the participants then reviewed the headings as a group.

### ***The focus groups***

The first group (03/03/2008, 5 participants) were asked to develop 4 key headings that they felt best represented their understanding of the value of the Admiral Nurse. By examining the values they decided on: Meeting the needs of the carer (1); Admiral Nursing (specialist role) (2); Collaborative Working (3), and, Admiral Nursing *for dementia* (4). The group was then able to focus their attention on collapsing and grouping the ‘values’ into the four headings. They discussed how they felt some values seemed to overlap with each other and how they may have different meanings for carers, people with dementia and Admiral Nurses; particularly the word friendship. The use of the value friendship generated a lot of discussion again and in these focus groups the consensus was that in the context of describing a

professional relationship it was not helpful and was removed from the values. It was, however, felt to be important in describing the value of peer support and the support of *for dementia*.

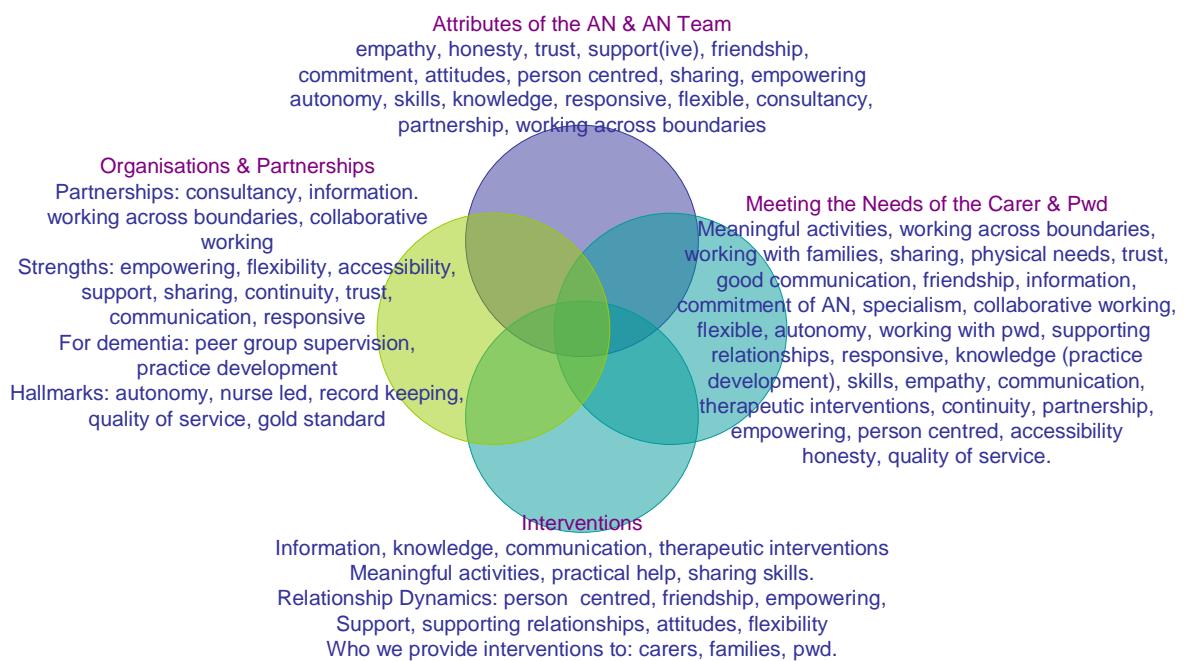
The second focus group was held on the 03/04/08 and this was the largest group with 17 participants. It was a group larger than I would have preferred but constraints to participants' time and access to the venue would have further held up the data collection to the study. The constraint of completing the study in a fixed amount of time continued to be a tension for me throughout the data collection process as it did not allow for practical crisis like rail delays, illness and cancellations of group meetings.

The group felt comfortable with working with each other and began by reading through the list of 40 values to highlight any issues or queries they had. 'Friend' was again raised as a possible issue for professional practice, as were meaningful activities/practical help and meeting the health care/mental health needs of the carer. Meaningful activities/practical interventions was queried as not being described clearly, the group discussed the use of psycho social activities and concluded that meaningful activities is the language a carer and person with dementia would most probably use. As the phrase had been generated in the discovery phrase it was already a validated term and this discussion further validated its use. The use of meaningful activity arises from the ability to provide environments that actively encourage pleasurable activity. This may be eating, drinking, playing games, reading; the list is not exhaustive. It is about recognising the person with dementia's 'experience' in everyday life. In the focus group people with dementia talked about being able to talk freely about having dementia and joining in with games and activities without judgment from others. It was agreed that meeting the needs of the carer was too broad a term. The group discussed

how the needs would be identified with an individual carer during assessment and would then be supported by the relevant intervention (practical or psychological) as far as practicably possible. The group then divided onto 4 tables with 4 or 5 participants on each table. This allowed for in depth discussion about headings and placing the values under the headings on the flip charts. The headings that were chosen were: Attributes of the Admiral Nurse and Admiral Nurse Team (1); Meeting the needs of the carer and person with dementia (2); Interventions (3); Organisations and partnerships (4). Values were then placed with the participants chosen heading (figure 7).

**Figure 7 Focus Group 03/04/08**

## Focus Group 2



The third focus group on 08/05/08, included 9 participants and 2 observers (one observer was a student nurse and the other a stakeholder). I spent some time with the student nurse explaining/giving written information about the research study and the reason she would not be able to participate (i.e. constraints of ethics as this person was not part of the Admiral Nurse or *for dementia* service). The group were, however, happy for her to observe the group process as part of her learning contract. Two participants were stepping onto the study, they completed written consent and I checked verbally that they were present in a voluntary capacity. The dynamics of the group did not feel as comfortable as when I facilitated the first focus group with them, as they appeared less willing to actively participate and required a lot of prompting. The entry into my reflective diary explores this,

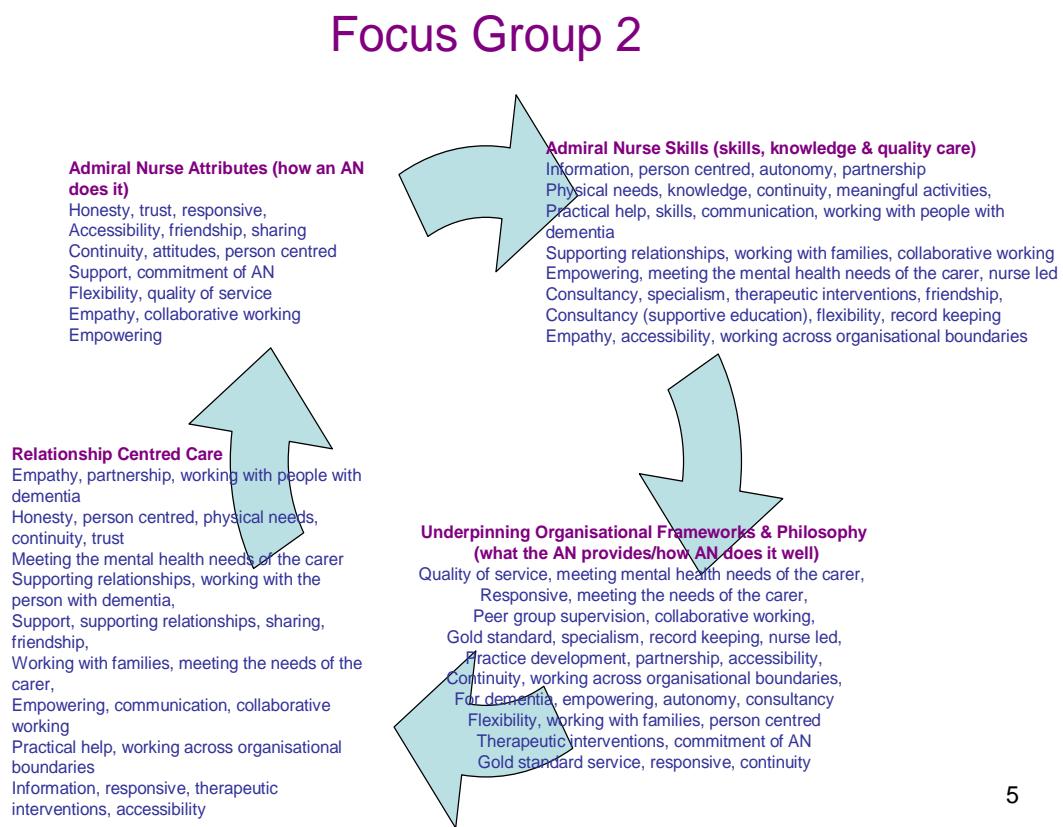
*'Each participant was asked to look at the list of values for a few minutes on their own and identify any questions they had about the 'values'. This did not generate a lot of discussion and the group appeared to find it heavy going. I am not sure if they did not understand or were just feeling 'over loaded' with issues outside the research study. To try and generate some enthusiasm I asked them to progress with thinking about how the values could be themed.'*

The reason for this happening could have been due to the fact that I had been booked to facilitate the group the month before but had been severely delayed on the train and could not make the allotted time. What followed felt like a very awkward conversation about headings. The contributions were: person-centred/family-centred/relationship-centred; Admiral Nurse skills/tools/core skills; professionalism; organisational values and philosophy; organisational underpinning support and ways of working. These were then in turn collapsed into, Admiral Nurse Attributes (how an Admiral Nurse does it) (1); Admiral Nurse skills (skills, knowledge and quality of care) (2); Underpinning organisational frameworks and philosophy (what an Admiral Nurse provides and how an Admiral Nurse does it well) (3) and relationship centred

care (4). The values were then placed by the participants under each heading in the way previously described (see figure 8).

**Figure 8**

**Focus Group 08/05/08**



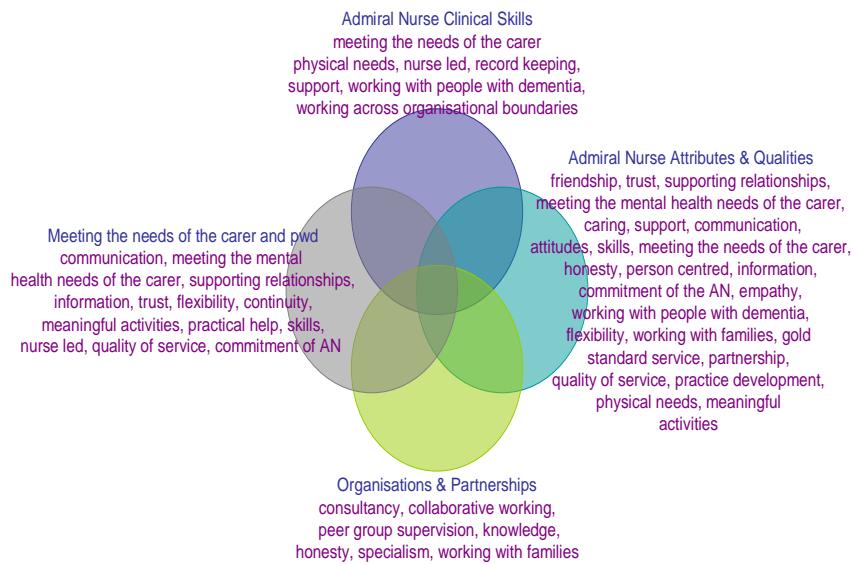
Whilst placing the values, participants raised an important question: How does an Admiral Nurse work and how do they do it well? As the group discussed the values and placed them under headings the answer to the question became clearer. The headings they chose provided 4 key principles with a set of underlying values for each. Some values overlapped with other principles, which was a matter of concern for some participants who would have preferred a ‘cleaner’ format. It was during this group that the four key principle of an Admiral Nurse began to emerge and were later developed and matured by the following groups and stakeholders:

The group on the 02/05/08 were very welcoming and eager to find out how the research study was progressing. The group split onto two tables to make communicating easier, the people with dementia sat with their respective carer and a friend on the other side of them. One carer said that her husband would not be useful in the group. I kindly reassured her that his contribution would be very valuable as everyone was invited to participate as they felt comfortable. He was very keen to help with the arrangement of the room and make sure everyone was comfortable and at the end he helped collect the furniture and put it into its original order. The group kept the suggested headings and spent a lot of time discussing where each value should be placed. They welcomed the values of trust, honesty, friendship, attitudes and supporting relationships. When discussing how they value working with an Admiral Nurse they placed the following values highly, meeting the needs of the person with dementia and the carer, nurse led, continuity, practical help with many of the values from attributes and qualities overlapping (see figure 9).

**Figure 9**

**Focus group 02/05/08**

## Focus Group 2



## **Summary**

The basis of the value of the Admiral Nurse is emerging here as a relationship based approach that is supported by data collected in the focus groups. My reflexive account of my own experiences in Chapter 1 began this thesis with the notion that we are all individual and each of us will use our life experiences, knowledge and skills in different ways depending on which way our lives are eventually mapped out. We do choose emotional journeys we grow into them sometimes with excited expectance and sometimes in crisis with trepidation. The emerging theory in this thesis shows that relationships with others continue to be made; how we stabilise them is dependent on who we meet and what outside influences occur. Carers recognise that relationships change throughout the caring trajectory; they welcome relationships where trust and partnership working can be developed. It has also begun to emerge that the Admiral Nurse is valued predominantly for meeting the needs of the carer alongside the person with dementia using a friendly and knowledge led approach. In the next section the data collection moves to the design stage of the 4 'D' cycle.

### **6.3 Design**

In the design stage I facilitated dialogue between participants to share positive stories with others so as to build on the themes developed in dream stage. The stories and content of the discussions became the vehicles for bringing out the positive core; following the process of coding using a constant comparison approach the stories were co-constructed by the participants to start to identify common themes.

In the design stage the participants 'determine what will be' that is, identify the internal and external relationships between the two strands of data collection (the social architecture). The participants at this stage worked together to craft and co-construct the data into positive

meanings for each group. The groups developed and agreed one set of provocative propositions. The provocative propositions challenged the interpretation of the data and thinking of each group in a confident and positive way. Two focus groups were facilitated in this stage, one with some of the carers who participated in the telephone interviews, photographs with narrative and the other with some of the participants from the Admiral Nurse, carers, people with dementia and stakeholder group.

### ***Building the Provocative Propositions***

During the dream stage the following four themes of stabilising relationships were co-constructed with the carer participants: stabilising the relationship between the person with dementia and the carer (1); stabilising family relationships (2); professional relationships that stabilise (3)and stabilising relationships to ‘move on’ (4). Alongside the data, four principles of Admiral Nursing were identified, supported by a set of values: Admiral Nurse clinical skills (1); Admiral Nurse attributes and qualities (2); meeting the needs of the carer and person with dementia (3) and working across organisations and partnerships (4).

The data were once again coded and using a constant comparison technique with notes from my theoretical diary 02/06/08, a set of provocative propositions challenging the interpretation of the data in the dream stage of the 4 ‘D’ cycle were developed: clinical skills (1), attributes and qualities (2), meeting the needs of the carer and person with dementia (3) and working with organisations and partnerships (4).

#### **1. Admiral Nurse Principle: clinical skills**

Value to carer:

To be confident in using my skills as a carer I require the continuity and flexibility of specialist knowledge and skills about dementia, physical care, communication and

management of change. My relationship skills are well established based on long-term knowledge, commitment and love for the person I care for.

## 2. Admiral Nurse principle: Attributes and qualities

Value to carer:

The relationships I have with the person I care for, my family and friends are essential to my well-being. The relationship I need with the Admiral Nurse has to be continuous, flexible and have accessibility. In order to sustain these relationships I require specialist information and therapeutic interventions provided by an Admiral Nurse.

## 3. Admiral Nurse principle: Meeting the needs of the carer and person with dementia

Value to carer:

I am me. I need to be recognised and listened to, to build an honest and trusting relationship with an Admiral Nurse. The relationship with my wife/husband/daughter/son is an essential part of my wellbeing. I know my wife/husband/the person I care for better than anyone professional; our relationship requires nurturing and understanding in the wider context of dementia.

## 4. Admiral Nurse principle: Working with organisations and partnerships

Value to carer:

I have skills that support my engagement with organisations and working in partnership with them. To be able to navigate positive outcomes with these organisations I need an advocate who is flexible and accessible with specialist knowledge in dementia care.

The two focus groups were designed to bring as many of the participants together as possible from both parts of the study; carers who had participated in the telephone interviews and visual methods with narratives in one group (1) and Admiral Nurses, carers, people with dementia and stakeholders in another (2). Both groups were audio recorded as smaller numbers of participants were anticipated and a note taker invited to group 1. All participants and note takers gave written consent to participate at the beginning of the study. This was checked and participants were reminded that their participation was voluntary at the beginning of both groups.

### ***Focus Groups***

This was the first time (25/06/08) this group had met, as in the discovery stage they undertook telephone interviews. Seven carers were able to attend with the co-ordinator of Uniting Carers *for dementia* attending as note taker. The participants were pleased to be able to meet each other and keen to discuss their experiences of being part of the research as well as their findings. This was the first time they had a complete overview of the telephone data and the visual and narrative data, although each had privately seen their own data to remove anything they did not feel was appropriate to include in the thesis or share with others. The data were collected using a note taker to compliment the audio recording and with the use of a flip chart and note pages for the participants' use.

The process of co-constructing the data began with a discussion about how the telephone interview transcript data merged with the photographs and narratives. However, the group reflected that describing their experiences in an affirmative way had at first been difficult to think about and wanted to emphasise the difficulties, both emotional and physical, they faced each day. They felt that this had been reflected in the telephone interview data. However, by narrowing it to the photographs and narrative; the data were highlighting the positives and

feelings of well-being could be construed to be out of context with the negative aspects of the caring role. It was not the intention to ignore the problems and distress the caring role holds but to enhance the profile of wellbeing and high level of skills carers have to provide a base for new knowledge and service improvement for carers and people with dementia. With these points clarified, the group quickly engaged with data to share experiences, thoughts and stories about their caring roles.

The key themes and related values from the dream stage of the data collection were firstly fed into both focus groups for discussion and then the provocative propositions were discussed and co-constructed by the participants.

### ***Focus Group 1***

Firstly the group discussed the findings of the carer, people with dementia Admiral Nurse and stakeholder group.

#### ***1. Admiral Nurse Clinical Skills***

The Admiral Nurse was valued for the ability to give information that was timely and appropriate in amounts the carer could understand and use to meet a particular need. This gave feelings of being supported and recognised for the role the carer was undertaking,

*‘Only when an Admiral Nurse turned up was there constructive support.’*

(Quote taken by note taker)

The communication skills of the Admiral Nurse were highlighted as being a high value,

*‘In hospital they didn’t talk in a language that could be understood.’*

(quote taken by note taker).

As the participants started to talk about Admiral Nurses’ knowledge, they began to identify their own skills and attributes,

*'we are actually the experts in dementia, and we have to cope with it on a 24 hour basis, yes, we do have fantastic knowledge of dementia.'*

(Carer A4)

However, carer A9 went onto say ..... '*but we do not always recognise that we have the knowledge.*'

Carer A4 supported this with the statement,

*'I recognised my husband's difficulties I do have tremendous expertise and it gives me tremendous confidence.'*

Accessing information was discussed as being time consuming and a mire of confusing bureaucracy and paper work; for example, carer A7 explains,

*'it is difficult to keep up with the legal aspects of caring for someone with dementia and I think that it is quite important part of getting information ..... it is very complex.'*

Carer A4 and A7 highlighted the importance of physical care and support with the knowledge of medication for the person with dementia,

*'if they fall and bruise themselves very badly you have to learn to live with that ..... when they become incontinent, no longer feed themselves ..... there are a whole series of physical manifestations that occur ... " and "the prescription of drugs is now recommended to be limited .... at some point they have to be withdrawn and the person stabilised again .... this was a very scary part of my mum's time spent in hospital....'*

## ***2. Admiral Nurse Attributes***

The attributes of the Admiral Nurse were warmly shared amongst the group,

*'an Admiral Nurse turned up on my door step like a saviour, very early on she was there until the end.'*

(Carer A6)

The Admiral Nurse was able to offer continuity to the carer where others had not been able to. As the caring role progressed, the accessibility and flexibility of the Admiral Nurse was valued. Other services had withdrawn, deeming that the person with dementia no longer had a

need for that particular service and thereby leaving the carer with no support. Carer A4 describes this in the context of caring for her husband at home with end stage dementia,

*'we have lost everyone we had there is no one now, no district nurse, no social worker ... I need guiding in the right direction, am I doing the right thing, why am I doing this?'*

The note taker captured some of the feelings this discussion disclosed,

*'the Admiral Nurse helped me understand, I didn't feel stupid asking again and again. It was a relief to have someone to work alongside you.'*

The Admiral Nurse support was also valued in helping with decision making,

*'I was uncertain, with the Admiral Nurse backing me up that helped me make the right decisions and gave me confidence.'*

(Carer A7)

These examples show that the Admiral Nurse approaches the support of the carer using empathy, confidence building and accessibility in order to work in partnership with the carer rather than 'doing things for them'. The relationship between carer and Admiral Nurse continues over a period of time and was interpreted as an attribute. However, it was highlighted during the discussion by the note taker that in some areas the Admiral Nurses were no longer working alongside the carer for the whole caring trajectory. When discussing an ideal interaction with an Admiral Nurse, the following examples were discussed:

*'the Admiral Nurse needs to carry on after someone goes into care..... this should be decided by the carer and the nurse'; "I would have liked to have seen an Admiral Nurse after my mum died;" and "to have an Admiral Nurse as early as possible so you have someone who knows you.'*

### ***3. Meeting the needs of the carer and person with dementia***

The group discussed how hard it is to maintain relationships within a caring role and to keep the person with dementia as the focus of care when they require support emotionally and sometimes physically themselves. The group identified 4 reasons for this:

1. Professionals making assumptions that a carer wants to care for the person with dementia. Carer A7 describes this,
2. Balancing the needs of the person with dementia as well as their own is a difficult and emotional journey for the participants as carer A4 explained.

*'I personally haven't lost my grand children but I have lost a large junk of their lives. I haven't followed them the way I used to and I regret that sometimes I cry about it really because I think it is very sad.'*

3. Not being able to recognise their relationship with the person with dementia due to the symptoms of their illness and the loss they feel. A7 describes how this feels when there is no support available,

*'I think bereavement is a big sense of whatever your relationship is not only as a wife or husband but also for me as a daughter my mum ..... is only alive now because she is breathing and the longer it goes on the harder it gets.'*

4. Balancing the relationships the carer has with other family members and wider friends and colleagues was a tension that caused the participants stress and burden; A5 explains,

*'..... the Admiral Nurse would help, you could talk about resentment, my Admiral Nurse understood enough to know that there were so many other things that needed to be taken care of ....'*

#### **4. Working across organisations and partnerships**

The amount of pressure that carers are put under to contact and work with organisations across health and social care and the voluntary sector was highlighted as requiring a lot of support. Carer A5 described her feelings about engaging with services,

*'I would say I probably have the skills to communicate with other organisations but whether I have the time and knowledge is another question ..... you don't always have time to learn everything that you need to know to be able to ask the right questions or deal with the problem you are trying to deal with ..... there are not enough hours in the day.'*

Carer A4 described that caring 24/7 leaves you with very little energy,

*'I have energy but not always, giving 24 hour care to a person you can't do it. For example when you have finished scrubbing carpets in the middle of the night.'*

Carer A5 agreed, saying,

*'you need to work alongside somebody else unless you are a person who really wants to do it all by themselves.'*

Secondly the group discussed the co-construction of the data collected by their own group.

The participants examined the data that had been collected in the telephone interviews, photographs and narratives and the carer, people with dementia, Admiral Nurse and stakeholder group. The overall theme of the discussion was that a caring role is relationship based and the relationships are ‘caring relationships’ that continue as part of everyday lives. The flow of relationships emerged, illustrating how carers managed their transforming and developing relationships when caring for a person with dementia. Each stage is described here with the associated properties and processes: recognising (1); transforming (2); stabilising (3) and moving on (4).

### ***1. Recognising***

Recognising existing relationships was pivotal to how carers managed their ongoing caring role. Their relationship with the person with dementia was always central to that recognition. Times when recognition was difficult were identified such as during the process of assessment and diagnosis and at times of managing difficult or changing symptoms of dementia. Carer A7 explains about her experience,

*'I had a very good relationship with my mum but unfortunately my mum had a bit of a bumpy relationship with my dad and when she first became ill I think it was quite obvious that he was not going to be able to take on board umm her care which is why I stepped in picked up kind of what needed to be done to get her to see a G.P. the psycho geriatrician and then you know we worked through the whole set of permutations until she went into care.'*

(Carer A7 focus group)

Feelings of responsibility also featured heavily in the narratives and discussions,

*'.....I think the commitment is there as well because dementia isn't something you can dip in and out of, if you're in it you're in it for the ride and that is why in some families one person really picks up that responsibility or sometimes because of distance or in my father's case has difficulty in understanding that it often falls to one person so it is a true commitment.'*

(Carer A7 focus group)

The importance of recognising that sometimes the relationship has been previously fractured but the person still wants to care now the roles can be reversed was highlighted.

*'.... it was very difficult to love that person, yes and some people have never loved their parents or the person they are looking after. Then they have difficult relationships but want to care.'*

(Carer A4 focus group)

'Recognising' the relationship was intimate and special to each carer. Sometimes the changes in the relationship were supported by day to day activities and sometimes by spending small snatches of time with each other. Carer A4 illustrates using photograph and narrative A4 4/6 how spending time together is recognition of tenderness and intimate relations that she has with her husband. She also holds memories that help her recognition and although times have been extremely difficult practically and emotionally she is able to reflect on her role as a carer in a positive way, see photograph and narrative A4 6/6. Lastly there was a period of recognition in the way that the relationships change to feel inclusive in larger family groups. Despite the tensions this can cause in juggling the different relationships, the person with dementia remains central, as illustrated by A3 in photograph and narrative A3 6/6.

The recognition of carer relationships came at an individual time and depended on the experiences of each carer. The recognition did not necessarily occur suddenly but was more commonly a gradual, insidious way of the relationships flowing that could occur many times;

adjusting and configuring throughout the caring trajectory. The participants in group 2 identified how the Admiral Nurse supports the recognition of relationships when they are working with a carer, as A4 reflects,

*'the relationship it doesn't mean anything if you don't try and work it out what people (carer) want in the relationship .... be practical as well, being honest with people (carer) and being there to share things.'*

Participant A5 goes on to explain,

*'...there is a huge shift in life and what they (the carer) are saying as well it is about being guided through that shift they see their role as well its enabling, ..... supporting and engaging them (the carer).'*

## ***2. Transforming***

As the caring role became embedded in each person's life, participants were capturing the relationships in ways that showed their transformation. This occurred at different times for each participant. A7 explains in photograph and narrative A7 4/6 how the family was involved in the changes in this relationship when her mother was attending day care. A feeling of pride and dignity was central for this change to take place. Carer A5 felt this was important for her as well when discussing involving services and other health and social care professionals.

*'.....maintaining relationships with family and future generations, reminds me of the feelings generated when I visit my mum.'*

(Carer A5, 26/11/08)

When relationships became difficult, for example, this was most often when the person with dementia had suffered a period of difficult or distressing symptoms; the relationships with others were even more important and although they may have changed from how they were previously configured they were central to the life of the carer. Carer A4 explains this through photograph and narrative A4 5/6. Information and the sharing of knowledge and skills were also important to the transformation of relationships. Without this being given in a

timely, constructive and understandable way this process was delayed. Sometimes the relationships were transformed by new people being introduced into the carer's life as A2 illustrates in photograph and narrative A2 4/6.

Memories remained central to being able to enter into the transformation phase. Music, hobbies, recognition of the person with dementia and past achievements were important, A4 articulates by using photograph and narrative A4 3/6. Transitions in care are traditionally seen as difficult and sometimes fracturing times for carers. However, it is well known that difficult to manage symptoms and the health of the carer can often mean that an alternative care setting can be a positive outcome, transforming the carer's relationships. Carer A6 explains through her photograph and narrative A6 1/6.

### ***3. Stabilising***

Stabilising of relationships was achieved at different times, sometimes overlapping with transforming. Stabilising was not necessarily permanent and could be an ongoing process with no particular time frame. It was about finding other ways of developing and maturing the relationship with the person with dementia and others. Carer A4 talks from her photograph and narrative A4 1/6 about when she and her husband became flat bound; she found other ways of connecting to people and the things around them. The feelings about the stability of relationships were also acknowledged by the participants in the focus group,

*'Understanding the impact of caring showing that nothing is trivial, a depiction of peace and tranquillity.'*

(Quote from a carer in the focus group by note taker)

Finding ways for the relationships with the person with dementia to be meaningful and fulfilling were central to this phase. Practical ways of involving the person so they felt included, safe and able to achieve were very important to each participant. Carer A3 shows

how important this is for him and his family in photograph and narrative A3 4/6. Carer A5 further supports this when illustrating the importance of when other people are involved in the person with dementia's care. Personal care and getting to know the person's likes and dislikes were central to this; as she describes in photograph and narrative A5 5/6. Other carers showed how finding a practical solution to difficult symptoms can change how the relationships work. The 'simple fish finger' was particularly significant for carer A6 powerfully illustrated in photograph and narrative A6 5/6.

#### ***4. Moving On***

Developing relationships after the person with dementia has died or is being cared for in a care home environment can be an extremely distressing time for carer relationships. This is also a time when most services withdraw their care, leaving the carer feeling lonely and forgotten. In the photograph and narrative A1 1/6; 3/6, the carer describes how things at home and in the local environment can support this process, which is often done alone with no professional or family support. The relationship can change again when the person with dementia is being cared for in a care home. This can be an important time for reviewing and developing their relationships. In photograph and narrative A2 5/6, carer A2 remembers happier times with friends and family. Others carers attain this by developing new relationships; for example, within the care home setting. For this to evolve the carer had to have confidence in the people caring for the person with dementia. A7 and A9 were reassured that their relative was central to dignified and person-centred care as supported by the photographs and narratives A7 1/6 and A9 5/6.

#### ***Co-Constructing the Provocative Propositions***

Once the group had co-constructed their data from the telephone interviews, photographs and narrative they began the process of co-constructing the provocative propositions (taken from

note taker notes, 25/06/08). Below are the four principles of the Admiral Nurse with associated/underlying carer values:

### 1. Admiral Nurse principle: Attributes and qualities

The Admiral Nurse prioritises relationships and care in family life, you can talk about feelings. You can become isolated from your family and become angry and resentful. He/she talks to you and other family members helping you to recognise the shifting roles and responsibilities. The relationship with the person with dementia can be good but the shared memories become neglected.

Value to carer:

The relationship I have with the person I care for, my family and friends can be stressful and raise a sense of loss. The relationship I need with the Admiral Nurse has to be continuous, flexible and have accessibility. In order to stabilise these relationships I require specialist information and therapeutic interventions provided by an Admiral Nurse.

### 2. Admiral Nurse Principle: Organisations and partnerships

The Admiral Nurse is an integral part of the health and social care team so has the knowledge of the area and services. You (the carer) need an advocate to help you make decisions; for example, continuing care issues. It is important to be able to talk about the sense of loss in my life with the person with dementia and my family. The advocate could be the Admiral Nurse or the most appropriate person but the Admiral Nurse should remain working with the carer. The Admiral Nurse was valued here for skills, time, up to date knowledge, trusting and guiding; she asked me, ‘Do you want to care?’ There is respect, choice, confidence and the ability to share the burden of caring with the carer.

Value to carer:

To be able to navigate positive outcomes with organisation I need an advocate who is flexible and accessible with specialist knowledge in dementia care, to give me confidence to use the life skills to facilitate my engagement with other organisations and work in partnership with them.

3. Admiral Nurse principle: Meeting the needs of the carer and the person with dementia

The stabilisation of the relationship between the carer and the person with dementia occurs at different times throughout the caring trajectory, sometimes being sustained for a long period and sometimes overlapping with ‘moving on’. Stabilisation had to coincide with the carer valuing themselves and the role they had found themselves in when the person with dementia first showed the signs and symptoms of dementia or they became involved with their care. The personal values the carers in the group identified were: ‘I haven’t given up’; ‘I am challenging and direct’; ‘I am resilient and committed’ (to caring); ‘I am patient’ and ‘I am proud of caring until I couldn’t any longer’. These were comments noted by the note taker on the 25/06/08 and are not direct quotes from the participants.

#### Value to carer

I am me. I want to be recognised and listened to. I am not anonymous; I want to maintain my individuality. I want to build an honest and trusting relationship with an Admiral Nurse. I know my wife/husband/the person I care for better than anyone professional. The physical and emotional care of the person I care for requires nurturing and understanding in the wider context of dementia.

#### 4. Admiral Nurse Principle: Knowledge and skills

The group discussed how it was important there was understanding of the impact of their caring role; for example: reversal of roles, personality changes (person with dementia),

physical changes that manifest themselves into changes in behaviour and bereavement. They emphasised that it was about the management of change and that the word ‘love’ preferring to use the phrase ‘desire to support them’ which they felt better reflected the diversity of the carers’ relationships with the person with dementia; for example, a neighbour or friend.

Value to carer:

To feel stable in using my skills as a carer I require the continuity and flexibility of specialist knowledge and skills about dementia, physical care, communication and management of change. My relationship skills are well established and based on long-term knowledge, commitment and desire to be there for the person I care for.

### ***Focus Group 2 (Carer, Admiral Nurse, Stakeholder)***

This group was timed to avoid the summer break and an 8 week notice period was given to the group (11/09/08). Unfortunately, even with reminders, the take up by participants was not as high as previous groups. This may have been due to time constraints because of responsibilities of caring and service provision or that the group was held in London which meant travelling for the majority of people. London was chosen for the pragmatic reason of having access to a large teaching room and facilities for all abilities. Transport and respite costs were offered and support with travelling for people with dementia. However, the number of volunteers for this group was small but did represent participants who had taken part in the previous groups. There were four participants: 1 carer, 2 Admiral Nurses and 1 stakeholder. The group was audio recorded and notes were taken on a flip chart and by individuals. With permission, their notes were shared with me at the end of the group.

Group 2 began their discussion by developing the carers’ themes and co-constructing the Admiral Nurse principles, developing how the Admiral Nurse supports the 4 identified carer relationships, recognising (1); transforming (2); stabilising (3) and moving on (4). The group

worked together to build on the values and principles of the Admiral Nurse and developed a link between how group 1 had identified the key themes of ‘caring with relationships’.

### **1. Recognising**

Recognition of the carers’ role occurred at points of transition; for example: diagnosis and assessment, changes in behaviour or severity of symptoms met by the person with dementia are times when the carer is under the most stress and burden. The Admiral Nurse was more likely to become involved with a carer at these points in their caring trajectory. Admiral Nurse B describes what it feels like to build a relationship with a carer,

*‘knowing the individual and having that knowledge about them is so intimate.’*

Admiral Nurse A identifies this as an ongoing theme throughout the data collection,

*‘it goes across all of them .... relationships with all sorts of people ... with the person they are caring for, the other members of the family, with other carers and their ability to form relationships and how important it is to keep them going.’*

Working out what the relationship is and developing it as a professional relationship was highlighted as important so that the carer could recognise the different level of support the Admiral Nurse could give. Admiral Nurse A explains,

*‘I suppose what is interesting is what the relationship is it doesn’t mean anything if you don’t try and work out what people (carer) want in the relationship....’*

Recognising the relationship within the context of the carers’ existing relationships was discussed, this involved assessing the practical side of caring, as carerA6 /6 poignantly illustrated. Recognition tied together the values identified in the previous group, underpinning the principle of Admiral Nurse attributes and skills,

*‘being able to be honest with people (carers)..... and trust has come up ... more than anything’*

(Admiral Nurse A)

The carers' wider relationships with family members, friends and professionals were recognised as being fragmented or seen as separate elements with no way of joining them up,

*'..... relationships as well they split them between, because of the context I suspect about the relationships with the person with dementia and also the relationship with other carers or the family members and then the relationships with the professionals.'*

Admiral Nurse B recognised the changes that were necessary for this process to begin,

*'there is a huge shift in life and what they are saying as well is it is about being guided through that shift ..... it is enabling them to move on, its supporting them engaging with them ..... it is a new way of life for people (carers).'*

Also, Admiral Nurse A recognised how as a professional she is part of that process,

*'is it about normalising the experience of actually this thing we talk about is looking at the person not the illness.'*

The importance of recognising both the carer and the person with dementia as individuals then develops the recognition of the relationship by,

*'recognising the person with dementia as a human being" and secondly "and use the relationship as a way of making people feel that you know that they are not just a carer they are a person.'*

(Admiral Nurse A)

Admiral Nurse B sums this up by saying,

*'it is the relationship so it is number one for both sides (carer and Admiral Nurse). '*

## **2. Transforming**

Supporting the transformation of relationships was identified in group 2 as 'sharing values' or sharing family values. In group 1 transforming of relationships occurred after recognising the changes that had been made and finding a platform from which they could view achievement. This incorporated the sometimes quite radical changes that had occurred in their lives due to their caring role. Group 2 recognised the importance of sharing values and Admiral Nurse A talks of her experience,

*'to think about how difficult it is to be honest and actually you (carer) need someone else to sort of help you work through that stuff and of course when there is no real crisis in the family you can sort of muddle along.'*

Stakeholder D highlights how difficult it can be for this process to begin,

*'relationships change throughout the illness because you know if you have had a difficult relationship you can tend to start to feel sorry for somebody and you know your feelings can alter ..... I think it is very difficult for them because they don't understand their own feelings.'*

Admiral Nurse B,

*'having time to discuss things with people as well it is about sharing in the relationship umm and discussing what is important in life.'*

Carer C,

*'I think it is about appreciating what you do have rather than what you don't', P:  
"Shifting their focus? Yes, I suppose it depends on the individual really I mean you know it's a question if you are half glass full or empty.'*

Admiral Nurse A concludes with,

*'Admiral Nurses help people recognise the positive things that you know remembering the positive things is about the person you are caring for or remembering the positive things that you can do together that make your life a little bit more pleasurable.'*

### ***3. Stabilising***

Stabilising was identified by group 1 as occurring at different times, sometimes overlapping with transforming. The stabilising was not necessarily permanent and could be an ongoing process with no particular time frame. It was about finding other ways of developing and maturing the relationship with the person with dementia and others. When the burden and stress of caring becomes too much it often impacts on the carers' mental and physical health and support to stabilise the relationships of the carer becomes necessary. Admiral Nurse A reflects on her clinical experience,

*'most people I work with really were either their relationships with their family had fractured as a result of a situation or that they were just or needed some help to bring it back together again or they were very isolated.'*

She goes on to reflect on how restoring person hood for the carer can achieve a period of stability,

*'the relationship is a way of making people feel that you know that they are not just a carer they are a person.'*

Carer C supported this by saying,

*'I think medicine today in a way I mean the whole sort of umm approach to medicine and the medical approach has sort of umm forgets the human person that is there and Admiral Nurses don't do that, that is, they are there for you (carer).'*

Admiral Nurse B recognises the sharing of skills and knowledge that occur during the relationship with a carer,

*'the Admiral Nurse maintains and acknowledges the skills and knowledge of the carer maintaining their identity.'*

This was further developed by stakeholder D,

*'yes, sharing and handing on of the expertise so that cumulatively you actually are creating a bedrock of understanding.'*

Admiral Nurse B goes on to reflect the underpinning support that *for dementia* provides in supporting Admiral Nurse group supervision and practice development,

*'and we learn from each other (Admiral Nurses) because of the practice development and group supervision and forums we are all individuals and we all have different skills and we learn different things from each other about a whole array of subjects and care situations and from experience as well.'*

#### **4. Moving on**

Moving on was a theme identified by group 1 as a part of their journey where they had periods of time when they could realise their own personhood. Sometimes this was during their caring role when the focus of care had shifted and for others it was after the person with dementia had died, as movingly portrayed by carers A1, A5 and A7 in this chapter. Moving on for the Admiral Nurse initially generated discussion about discharge and referral criteria and how service configuration and delivery impacted on how they can support a carer along

their caring trajectory. To support a carer in moving on is clearly a very important part in how an Admiral Nurse works and has implications for service delivery. The way the relationship is viewed by the Admiral Nurse is not necessarily articulated in the same way by the carer. The value of a friend and friendship was strongly identified by the carers and people with dementia and discussed as a partnership that leads the way to enable a carer to move on, as illustrated in the following conversation,

Admiral Nurse A,

*'..... for dementia provides a structure that supports Admiral Nurses to become leaders.'*

Stakeholder D, "yes."

Admiral Nurse A,

*'but not actually a leader itself.'*

Admiral Nurse B,

*'but because it is there it creates a two way process it generates something for Admiral Nurses to give something back and enables us to develop our own practice in partnership with each other there are no specific leaders it is a partnership with each other.'*

(In the context of group supervision and practice development).

Admiral Nurse A,

*'the word friendship is there a lot.'*

Admiral Nurse B,

*'yes, I think that is something the carer recognises it is not necessarily what the Admiral Nurse recognises as a sort of role.'*

Stakeholder D,

*'is it one of those words in carer language is very acceptable but a professional feels is tricky?'*

Admiral Nurse A,

*'yes it gets challenged it makes people (professionals) feel uncomfortable.'*

The Admiral Nurse works in partnership with the carer, allowing them to build up alternative ‘maps’ of relationships. In turn the supporting charity, *for dementia*, supplies the support via group supervision and practice development to the Admiral Nurse. The two strands coalesce, linking up with other services and organisations with the carer at the centre of the interventions until a time where the carer can move on.

## **The Co-construction of Admiral Nurse Principles and Values**

By making comparisons of the data from both groups, the Admiral Nurse principles and values were then co-constructed: Admiral Nurse attributes (1); meeting the needs of the carer (2); knowledge and skills (3) and working with organisations (4), each with a set of underlying values.

### ***1. Admiral Nurse attributes***

The participants of the focus groups described an Admiral Nurse attribute as the individual’s persona, what they brought to the relationship between them and the carer. The underlying values were co-constructed as: friendliness; trust; caring; communicator(tion); attitudes; honesty; flexibility and commitment.

The use of the word ‘friends’ has remained a constant debate throughout this thesis with the participants debating the use and meaning of the word and its usefulness in describing a value of a nurse or the meaning of the relationship. The dilemma of how language is used by professionals and carers was discussed by all the participants but the concern remained with the Admiral Nurse and stakeholders that the use of the word ‘friend’ had an implication of a relationship developing beyond professionalism.

The first group was not alone in raising friendship as an issue, as they were supported by the group of 31/03/08, and the group of 03/04/08. Interestingly, the group of 03/04/08 placed friendship under attributes of Admiral Nurse and team rather than as a professional skill. The word friend was a concern for Admiral Nurses and stakeholders and this required further development and ‘unpicking’ in the dream stage of the 4 ‘D’ cycle, but essentially participants were articulating the value of the Admiral Nurse as having the opportunity to develop mutuality through friendliness between the Admiral Nurse and carer.

## ***2. Meeting the needs of the carer***

The groups spent a lot of time discussing this principle. Historically, the Admiral Nurse has primarily focused on the care of the person with dementia and then the person with dementia’s wider family. The underlying values were co-constructed as: communication; supporting relationships; flexibility; trust; honesty; continuity; sharing (of information, knowledge and skills); partnership; empowering; support (practical and emotional) and accessibility.

## ***3. Knowledge and skills***

By making comparisons with the data collected throughout the 4 ‘D’ cycle it is apparent from the emerging theory that Admiral Nurses are developing their skills, alongside working with carers as their primary focus. The underlying values for this principle were co-constructed as: communication; sharing; knowledge; consultancy; information (finding and developing); including the person with dementia; practice development; supervision; knowledge of therapeutic interventions and mental health.

## ***4. Working with organisations***

This principle was highly valued by all the participants. The ability to work across organisations was attributed to the supporting charity, *for dementia*, that supports the Admiral

Nurses' practice development and group supervision. They also provide the 'brand' of Admiral Nursing that supports the generic practice of the Admiral Nurse; this is highly valued and defined in terms of being a 'gold standard service'. This is not unique to Admiral Nursing as there are other nursing services supported by charities that are also highly valued by their service users and colleagues, e.g. the palliative care nurses who work within the Hospice movement and the Macmillan nursing service. The underpinning values were identified as: communication; accessibility; continuity; record keeping; autonomy; responsive; flexibility; collaborative working, knowledge and skills; partnerships and empowering.

The 4 carer relationships discussed in this chapter have further built on the 'positive core' of the discovery and dream stages by depicting vividly and sometimes movingly how carers adjust, develop and support their relationship throughout parts of their caring role. Although the carer relationships and the Admiral Nurse principles and values have been discussed in this chapter as if they are separate entities, in reality these themes relate to different dimensions of a carers' life and how an Admiral Nurse can support them. How the types of relationships play out in each of the carers' lives has been highlighted through their stories, photographs and narratives of their daily lives. The notion that relationships are lost and irretrievable when caring for a person with dementia is inherent to the discussion. This challenges the idea that carers have to live with continued loss and grief of lost relationships. For some carers the process of stability is ongoing, for others their lives have found stability; namely those whose person has died and who have therefore had some time to stabilise their relationships and move on. Below, the principles and values of the Admiral Nurse have been bought together as a set of propositions with the value of how the importance of relationships can be stabilised by the Admiral Nurse:

**Admiral Nurses' principles and values:** Admiral Nurse attributes – values: friendliness; trust; caring; communicator(tion); attitudes; honesty; flexibility and commitment.

**Value to carer:** The relationship I have with the person I care for and my family and friends can be stressful and raise a sense of loss. The relationship I need with the Admiral Nurse has to be continuous, flexible and have accessibility. In order to sustain these relationships I require specialist information and therapeutic interventions, provided by an Admiral Nurse.

**Meeting the needs of the carer:** Values: communication; supporting relationships; flexibility; trust; honesty; continuity; sharing (of information, knowledge and skills); partnership; empowering; support (practical and emotional) and accessibility.

**Value to carer:** I am me. I want to be recognised and listened to. I am not anonymous; I want to maintain my individuality. I want to build an honest and trusted relationship with an Admiral Nurse. I know my wife/husband/the person I care for better than anyone professional. The physical and emotional care of the person I care for requires nurturing and understanding in the wider context of dementia.

**Knowledge and skills – values:** communication; sharing; knowledge; consultancy; information (finding and developing); including the person with dementia; practice development; supervision; knowledge of therapeutic interventions and mental health.

**Value to carer:** To be confident in using my skills as a carer I require the continuity and flexibility of specialist knowledge and skills about dementia, physical care, communication and management of change. My relationship skills are well established based on long-term knowledge, commitment and desire to be there for the person I care for.

**Working with organisations – values:** communication; accessibility; continuity; record keeping; autonomy; responsive; flexibility; collaborative working, knowledge and skills; partnerships and empowering.

**Value to carer:** To be able to navigate positive outcomes with an organisation I need an advocate who is flexible and accessible with specialist knowledge in dementia care to give me confidence to use the life skills to facilitate my engagement with other organisations and work in partnership with them.

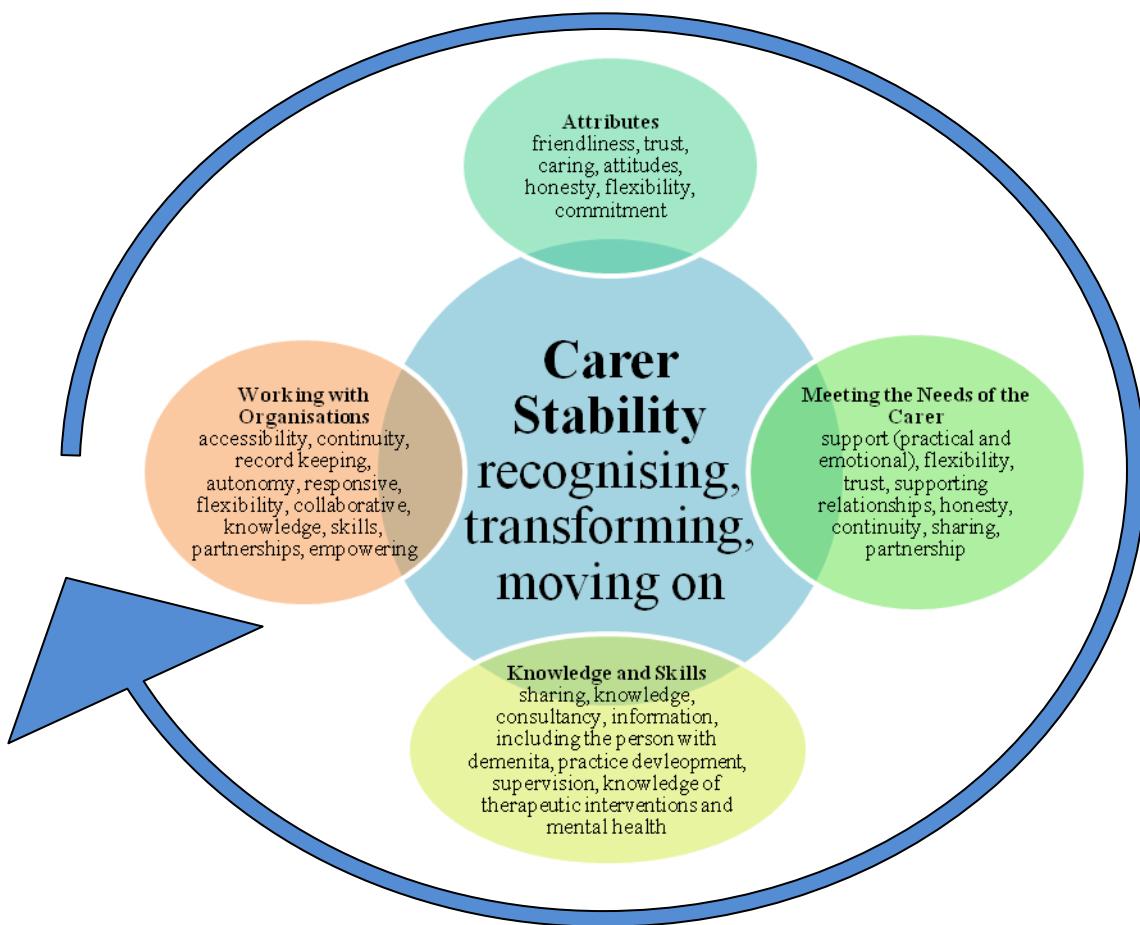
## **Summary**

The findings in the design stage further build upon the theoretical understanding of ‘caring relationships’: recognising, transforming, stabilising and moving on. It is evident that carers manage and support their own needs and those of the person with dementia, often struggling to find a point of stabilisation. Family and friends are closely entwined with the relationship the carer has with the person they are caring for and for various complex reasons the carers in the study have highlighted, they often require some help to support their own personhood to enable them to move on at points in their caring role. Alongside the theoretical understanding of the building of ‘caring relationships’ this study has identified four core principles with underlying values of Admiral Nursing that can support the carers’ ‘caring relationships.’ There are noticeable similarities with the approaches to family-centred care approaches previously discussed in Chapter 3. However, the model developed within this study provides a new approach to supporting carers’ relationships through Admiral Nurses. The 4 core principles: Admiral Nurse attributes (1); meeting the needs of the carer (2); knowledge and

skills (3) and working with organisations (4), and underlying values that have been identified give a working model to Admiral Nurses' practice (see figure 10).

**Figure 10**

**A conceptual model of Admiral Nurse Practice**



## **Chapter 7**

### **Destiny – completing the appreciative inquiry 4 ‘D’ cycle**

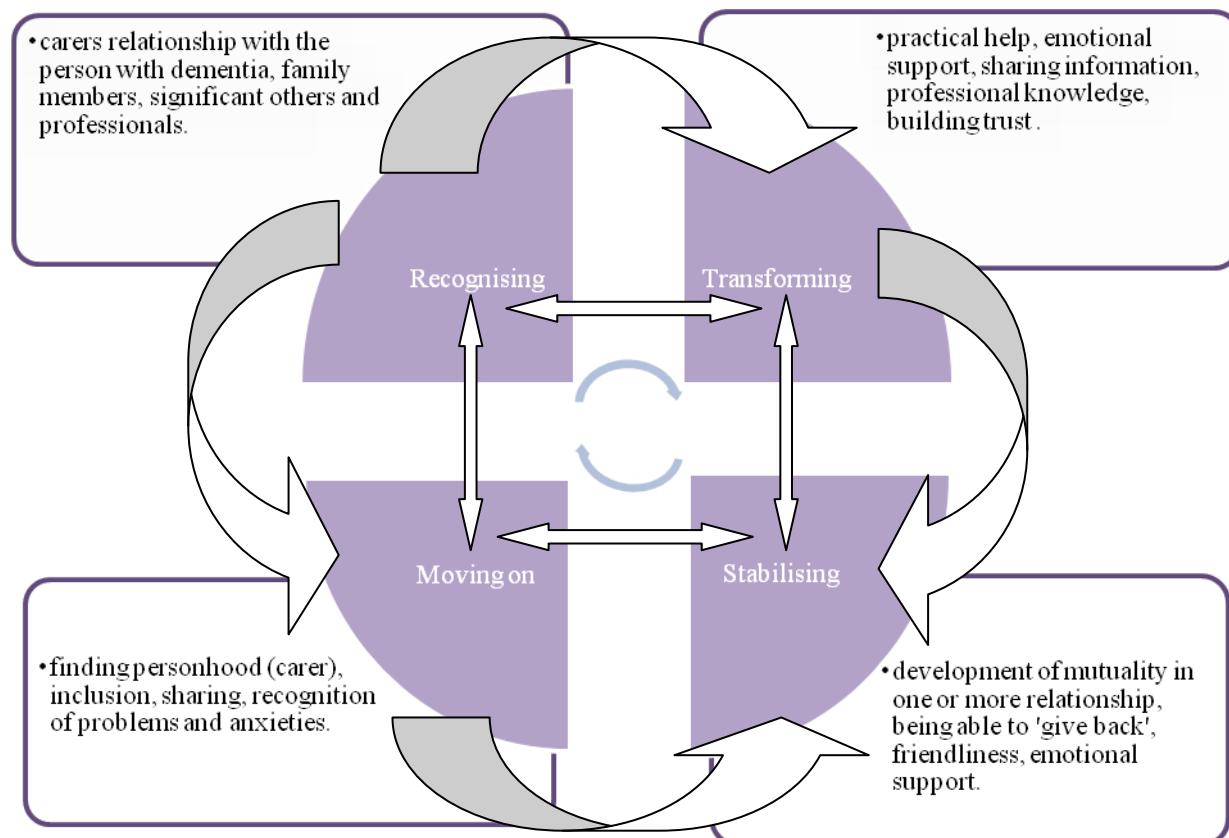
In Chapter 6 the typologies of caring relationships and the four core principles, and underlying values of Admiral Nursing were described. With this understanding as a focus, the inquiry moved into the destiny stage of the 4 ‘D’ cycle. Destiny is the final stage of the appreciative inquiry 4 ‘D’ cycle it is the ‘delivery’ or planning the delivery of what will be in the future (Reed 2007). This stage develops the activities and actions of previous stages of the 4 ‘D’ cycle, drawing on the future actions and commitments of the findings of the study.

The stories, photographs and narratives that were told by carers and presented in earlier chapters have portrayed the unique ways in which carers manage their day to day caring role. They told stories about private and intimate relationships within a family, coping and management strategies, feelings of loss and grief, seeking ways of gaining support and stability in their relationships and the struggles and accomplishments of day to day life as a carer of a person with dementia. This has identified that the life of a carer is a world of not only stress and distress but a diverse world of management and coping techniques, skills and knowledge and strong family relationships. The stories also highlighted how carers strive for a sense of self and wellbeing within their complex caring roles.

This chapter explores the way that carers actively seek ways of supporting and developing their caring relationships (see figure 11). The chapter goes on to focus on how a carer’s interaction with an Admiral Nurse can provide a period of stabilisation of the carer’s relationships. This is a support system that is created and can be maintained by the carer in partnership with the Admiral Nurse.

**Figure 11**

**Caring typologies: a conceptual model (a non-linear process where none of the phases are excluded)**



## **Typology of Caring Relationships**

The description of a family-centred approach gives different views of the family, some are subsidiary concepts but can still be thought of as having similar general perspectives. These elements include partnership, collaboration, participation and communication. Both the concepts of systems and value/psychological family-centred approaches emphasise the well-being of the individual whilst others imply a holistic approach to the family as a whole (Hutchfield 1999). These holistic models differ from the idea of the family as an indivisible unit or the family as a unit of care or the family as a system. The term ‘family’ is synonymous with family group, unit and/or system. A family approach is flexible as it allows for definition of each individual family and its conceptualisation, perspective and meaning to the individuals. In addition it allows for the flexibility of ‘professional members’ to support different individual priorities and take into account the uniqueness of each family group. Previous research with carers in the field of dementia care suggests the care of carers in isolation to the person with dementia can be a barrier to the person-centred approach (Kitwood 1997; Keady and Nolan 2003; Keady *et. al.* 2004)

Whilst sharing the ‘language’ of family-centred systems and value/psychological approaches the exploration of carer’s stories, photographs and narratives in this study shifted to reveal the complexity of maintaining a caring role from the perspective of value and wellbeing. The idea of finding positivity within a caring role has been reported in previous qualitative works (Schumacher *et. al.* 1998; Lombardo 2003; Andren and Elmstahl 2005; Nicholas *et. al.* 2009). This study adds to this body of work and focuses on the carer’s experience as being an individual. In addition, it is a significant determinant of an individual’s wellbeing and personhood during and beyond their caring role.

The carers had no guide book to help them as they made the transition from wife, daughter, husband, son to carer at a time of uncertainty and emotional vulnerability. Consequently they adopted diverse strategies and coping mechanisms to sustain and develop relationships within the family. Some were more successful in coping with this than others. Some of the carers faced diverse and difficult situations, having little influence over the way care was delivered to their person with dementia. Their efforts to gain the best care were often undermined by assumptions about their level of skills and knowledge and the availability of appropriate services.

There are two ideas that arise from the carer's stories, photographs and narratives. Firstly, the idea that the carer is the passive recipient of the role as a carer must be questioned. Whilst some people can willingly take on a caring role, other people are not so willing or are unable to emotionally or physically – is there a pragmatic choice? This is an alternative story and is an individual's construction of the narrative that gives shape to what it is to be a carer. Secondly, the findings highlight different ways carers strive to stabilise their relationships through diverse and difficult experiences. The interpretation of wellbeing and value in a caring role provides a different and complimentary perspective to much of the contemporary theory, which point to interactions and processes to support carer stress and burden by providing for the person with dementia (Carradice 2003; Roelands *et. al.* 2008). However, the findings from this study indicate that the interactions that carers value to support their personhood are also significant determinants of how a carer manages their caring role.

### ***1. Recognising the relationships***

The personal relationship with the person with dementia is always part of larger relationships and is never isolated to a one to one or solely an individual relationship between the carer and the person with dementia (Kitwood 1997). Each participant told their own story about how

other family members or relationships with professionals helped bridge the relationship with the person with dementia (Williams and Keady 2008). A9 described how her son helps with the care of his grandmother by helping with the difficult symptom of incontinence. A3 tells of how his father has become part of his family unit and the feelings of comfort and empowerment the family gain from this. A6 managed the particularly difficult symptoms of her husband's Pick's disease. She found that they became isolated from their friends and work colleagues, but family members, although not as willing to be as close before the dementia, were there to support them offering an important source of comfort. The examination of how person-centred care is delivered to the person with dementia at the expense of addressing the carers' personhood can be found in the existing literature. For example Adams (2005) highlights that relationship care can go some way to address this problem suggesting the work of Gilleard 1984 be re-examined. Gilleard's 1984 work provided us with a thread of analysis that underpinned living with dementia as more than just an experience of the person with dementia but one that extends to the whole family. This study further supports this theory suggesting that a shared approach to the care of the person with dementia that understands the intimate experiences of a carer is underpinned by 'being together' (Sheard 2004b).

Conversely, for A1 and A6 a feeling of comfort came with making relationships with health and social care professionals. They both had close and endearing relationships with the person they were caring for and with family members, however, the symptoms of dementia became too difficult to manage at home. Both participants experienced feelings of guilt and loss at the thought of no longer being able to care within the family home. They both struggled with how the person they were caring for developed relationships that were closer with professional staff. This made them feel like they had failed in some way, until they too

were able to develop new relationships with the same staff members (Nolan *et. al.* 2002).

This coincided with a recognition that the relationship between them and the person with dementia had changed.

Due to feeling so unwell and having an enforced stay in hospital A8 tells of how she has recognised her relationships with her family members and valued them as non judgmental and without burden. A1 found that he at last recognised the relationship his daughter had with his wife, something he felt had not been there prior to his wife's diagnosis of dementia. He recognised the development of his daughter's relationship with his wife and turned this to a positive feeling. He also found that the tasks and emotions he was struggling with at home were made bearable by the relationships he made with the care home staff. His relationship with the matron became so strong he entrusted his wife's last few hours with her, feeling she was there in the right spiritual medium due to their shared values, beliefs and culture (Clarke 1999).

The recognition of the changing relationship with the person with dementia was evident for each participant but differed depending on the circumstances of their caring role. This depiction of caring does not fully represent all the features of the relationship with the person with dementia. The same carers told stories about situations and experiences where they modified practical day to day aspects of their lives to support the changes in the relationship. Sometimes this was successful and sometimes did not show any evidence of how the emotional difficulties that they were coping with impacted on the practical. These carers believed that by making these sometimes life changing decisions they were acting in the best interest of the person with dementia, sometimes at the expense of their own personhood. This suggests that recognition of the changing relationship between carer and person with

dementia is a complex interplay between these two people that at times during the caring trajectory requires skilled and knowledgeable support.

## ***2. Transforming the relationship***

The transforming of a relationship occurs primarily in a practical way. This was sometimes introduced by the carer and sometimes by using a service, for example, day care. The transformation was not always long lived, for example when A4 used music and videos for a period of time it gave her and her husband some mutual time together that was enjoyable. Information sharing and giving supported the transformation of relationships. Receiving up-to-date and appropriate information in a timely fashion improved feelings of wellbeing and personhood. Conversely not being able to access the right information or to get others to listen to a worry or request was very distressing and led to physical and emotional ill being. What was important to the transforming of the relationship was for the carer to view the person with dementia as a person who could achieve an element of independence of choice and /or activity. For example A5's mother's ability to paint a picture and enjoy her nails being painted. Each carer did not play down the distress they encountered in trying to find a transformation in their relationships and indeed found the reflections hard to articulate at times.

Where the transformation of the relationship had been supported by a professional it was the qualities or attributes of that person that were essential to a successful outcome. The professional had to be knowledgeable about dementia and to be able to show flexibility in their approach to the care of the person with dementia. Spending time getting to know the person, building trust and honesty between the person with dementia and in turn the carer, was essential to carer wellbeing. The word friendliness has replaced the word friend as it better describes the feelings this relationship provides when supporting relationships. It was

also an important aspect of the transformation. Friendliness needed to include projections of the carer feeling in control i.e. working in partnerships with a professional who was welcoming and warm in attitude and manner. When the reference group met for the last time on 12<sup>th</sup> March 2009 they highlighted the importance of these qualities being included in this thesis.

### ***3. Stabilising the relationship***

As this study has demonstrated, people with dementia have a set of existing relationships with family members, friends and their wider social network that require support and recognition. Immediate and extended family members are seen to play a central role in a carer's life and their role cannot be overlooked when considering the needs of the carer and person with dementia. In photographs, carers A3 3/6 and A4 5/6 describe how the family brought recognition and stability to their relationships. Arguably the 'family members' can be people that enter our lives at different junctures, maybe for a short while as carer. A2 6/2 and carer A4 6/6 explain other people entering your life can capitalise on feelings of wellbeing and stability.

Pragmatically, the importance of relationships to finding and maintaining stability in caring lives holds significance to carers. Clarke (1999) identified the theory of 'normalisation' which is grounded in the relationship of the person with dementia and the carer operating by relating to the past and relating to the 'problem-free'. Other commentators have since recognised the significance of stability to carers (see for example: Nolan *et. al.* 1996; Sheard 2004b). Carers have an unenviable task striving to maintain the process of normalisation.

In order to talk about a time of well-being the trauma had to be discussed first, then the carer could start to discuss how a relationship changed or developed to a different level (Clarke

1999). For some of the carers this was with the support of a practical intervention, either by a social or health care professional or by a friend or family member. For the transition of ill-being to well-being to occur, it appears that carers need to be able to ‘give something back’ to a relationship. For this to occur there is a period of carer stabilisation and the development of mutuality within one or more of their relationships (Hirschfeld 1981 p. 162 and Hirschfeld 1983).

#### ***4. Stabilising the relationship to move on***

To discuss the interpretation of moving on I am going to return to Kitwoods 1997 work (see Chapter 2). What a carer needs to move on is as individual as that person; we have seen that no one story is the same. Concepts of need are always expressed within the carer’s cultural framework, and therefore influenced by those cultures meaning and values. Returning to Kitwood’s 1997 work (p82) I would suggest that carer’s needs are not unlike those of a person with dementia. They require elements of comfort, attachment, inclusion, occupation and identity. The necessity for comfort and warmth is required to support the feelings loss and grief and the endings of an established way of life. Bowlby, (1951) claimed that bonding is instinctive in nature, and that carers have experienced long established relationships that have acted as a safety net giving support in times of distress and uncertainty. As the person with dementia’s health declines the ability to draw on the attachment of this relationship begins to decline, leaving the carer feeling both isolated and anxious. Others have discussed carer isolation as a stressor and pre-determinant of poor emotional and physical health (Nolan *et. al.* 1996; Nolan *et. al.* 2004). The need for inclusion increases as the person with dementia declines. The stigma of dementia remains evident in today’s society. For example it becomes more difficult for a carer to make face to face contact and group contact with others because of their caring responsibilities (DH 2009). In addition remaining occupied in a personal way becomes increasingly difficult both in employment (as experienced by carer A9) and in day

to day living. A7 gives an example of the hour she has for herself when she returns from visiting her mother. Interestingly A3 had incorporated his weekend's activities with his father enjoying a visit to the pub each week. I would argue however that this would be a short window of joint activity which is further demonstrated in the case of A6 and their visits to the park. As the person with dementia became less able to maintain joint activities and the caring role became 24/7 the identity of the carer became more difficult to distinguish, causing anxiety and distress and in the case of A8 had physical manifestations. When I was interviewing carers in the discovery stage, each carer had to relate to as much of their whole story as they had time to. To some extent our identity is confirmed by others. Kitwood 1997, discusses this in the context of the person with dementia and I would argue that without the empathy and recognition of the uniqueness of each carer's story we are not recognising a carer's personhood and enabling them to move on with their lives (Kitwood 1997). As the carers who have participated in this study have demonstrated, moving on occurs at different junctures of the caring role. For example A1 was able to return to his voluntary work when his wife was living in the care home.

In many respects this conceptual model of a typology of relationships: recognising (1); transforming (2); stabilising (3); and moving on (4) identify our most basic human needs, to be valued, be involved with relationships that are recognisable and to be enabled or empowered as a person. However, there are differences. The caring typologies identify the carer as a person, being supported to return to an enriched life at their chosen point along the caring trajectory. External factors are also powerful influences on what type of support a carer receives. Health and social care policy, regulatory practices, market forces and, societal expectations and stigmas of the care of people with dementia, demographic and cultural trends all impact on the life of the carer. Therefore many factors are present at any given time

to affect the support of a carer. As these interact with each other, a chain response is put into motion leading to response from elsewhere in the system. It is a dynamic, complex interplay between meeting the needs of the person with dementia and the carer. These complex interactions are considered central to determining whether a carer maintains their personhood throughout their caring role or not. This is illustrated diagrammatically in figure 8 p.196.

Here the way an individual carer describes each dimension of their changing and developing relationships is depicted as the product of their construction of their stories. Photographs and narratives which are shaped by a range of facilitating and moderating factors within given contexts, circumstances and the strategies the carer and professionals apply. This is a complex situation that is constantly changing the carer's understanding and emotions underpinning their personhood.

### **A conceptual model of Admiral Nurse support to carers of people with dementia**

In figure 9 p. 197 the principles and values of the Admiral Nurse are depicted with the 'caring relationships' of the carer, supported by a representation of the facilitating and moderating factors within carer's relationships that influence an individual's experience. The complex interactions that take place between an Admiral Nurse and a carer are illustrated in the following example. Throughout earlier chapters we have followed the caring role of A1 and were introduced to how an Admiral Nurse worked alongside him whilst he was caring for his wife. The Admiral Nurse built a relationship with A1 that supported him in recognising the relationship he had with his wife and helped him to transform this with some help from local services. This was not however, without its difficulties and drew disparaging comments from others. The Admiral Nurse remained in contact with A1 and was able to work alongside him to manage complex practical interventions and complicated care arrangements. When A1

reached periods of stability within his relationships (these varied between family members, friends and professionals), the Admiral Nurse withdrew her face to face contact but remained in ‘touch’ at times of transformation, and these were frequent during A1’s caring journey. For example, the Admiral Nurse worked closely with him to support the acceptance of respite, finding a care home, managing his wife’s deteriorating health and eventually her death. The support continued during the period of bereavement giving time and space for A1 to transform his relationships again to find a plateau of stability. This was achieved by meeting face to face for a period of time and then introducing him to other relationships and ways of occupying his time.

The model presented here provides an explanation of how Admiral Nurses support carers through the complex and constantly changing trajectory of their caring role. The carers’ stories and the principles and values of the Admiral Nurse have been discussed in some detail in Chapter 6 whereas some of the facilitating and moderating influences have only been identified up to this point, so these are explored in more detail in the rest of this chapter.

### **Influences that facilitate how an Admiral Nurse supports carers of people with dementia**

Focus group 1 identified a set of Admiral Nurse ‘values’ that closely resemble the systems and value/psychological family-centred approaches described in the literature in Chapter 3:

- Empowerment (aims to psychologically give a sense of mastery and control to family, socially to empower a participatory competence).
- Negotiation (structuring expectations, valuing family involvement).

- Facilitating (communication skills - listening, silence, validating, acknowledgement of family skills and experiences).
- Information giving (participatory experiences – physical, psychological, social).
- Partnerships (relationships, decisions, collaborative practice, advocacy).

Further co-construction of the data shows the values of Admiral Nurse Practice compared to the literature in Chapter 3 (Freidmann 1989; Monahan 1993; Whyte 1997; Hutchfield 1999; Franck and Callery 2004) supported by the Admiral Nurse framework of practice development and supervision. However, the interpretation of how carers view periods of wellbeing and how they use existing skills highlight the importance of the relationships they develop and stabilise throughout the caring trajectory.

Data collected in focus group 2 previously described in Chapter 6.2 is an interpretation of the core principles and values co-constructed by focus group 3 (carers, stakeholders and Admiral Nurses 11<sup>th</sup> September 2008). The core principles have similarities to those described in the Modernising Nursing Careers Advanced Practice Characteristics, (Nursing and Midwifery Council 2006 and Royal College of Nursing 2008) referred to in Chapter 5 of this thesis. Advanced Practice has until now been characterised by a high level of clinical/technical competence. This type of competence is easily measurable as a technical outcome for example a reduction in blood pressure, technical diagnostic testing for bowel cancer. Measuring Advanced Practice using a benchmarking approach uses the idea that it is a level of practice rather than a particular role making it easier to articulate across the different context of supporting and working with carers relationships. NHS Education for Scotland (NHES 2007) has identified four over arching themes that articulate ‘advanced practice’ research, education and managerial and leadership roles. These themes are further supported

by underpinning principles, autonomous practice, critical thinking, high levels of decision making, problem solving, value based care and improving care.

Smith, Coleman and Bradshaw (2002) have previously suggested the following framework that has similarities to the principles and values of the Admiral Nurse. They suggest four phases: 1) build a therapeutic relationship by exploring strengths to facilitate future learning and empowerment of family. Prioritise the problems by talking to the family (listening, sharing perceptions and participatory dialogue). 2) Negotiated participatory experiences, containing three elements – physical, psychological, social. Physical: basic carer/nursing tasks, psychological: developing self-efficacy, self esteem, self confidence and coping skills and social: decision making, listening to family as a priority, advocacy skills. The aim of the framework is to enable a family to become competent in negotiated domains of care; promote self-efficacy beliefs, so that the family can take control from the professionals and set goals that must initially be short-term & achievable. 3) Implementation: the nurse has a ‘helping role’ e.g. modelling practical skills, sharing technical knowledge through teaching or information giving and finally 4) evaluation: Has the family developed negotiated competencies? Has an empowerment outcome been achieved (this may be part or all of negotiated competencies – aim for short-term initially). Yes rest/discharge family, no start cycle again.

The impact of meeting the carer’s needs to improve the quality of life for the person with dementia has previously been examined and there remains a tension as to whether this should be met by a different health or social care discipline or incorporated into the care of the person with dementia (Nolan *et. al.* 1996; Nolan *et. al.* 2004). However, there are implications here for Admiral Nurse practice. A carer of a person with dementia has existing

relationships with family members, friends and their wider social network that require support and recognition; this was an extremely strong theme throughout the study. A family-centred approach can support the work with the carer and family members with issues like loss and grief. Spending time with and getting to know the family enables the Admiral Nurse to identify goals with the family, information giving and work towards evaluation. It should be highlighted here that there are similarities to the already implemented ‘Nursing Process’ and careful consideration would be required to working with the caring typologies rather than the ‘process’ to maintain a truly family-centred care approach.

The carers’ stories also included strong feelings about the person with dementia being central to each carer. As described in chapter 2 Kitwood’s (1997) work is now well known in the world of dementia care and although this work has changed the way that care for the person with dementia is viewed and delivered, it has as yet made little inroad to the care of the carer. This seems to be very relevant to what the carers are saying in this study, carers often feel their relationship needs are in the shadows, if not ignored, giving rise to feelings of low self esteem and loss of confidence. Maintaining a sense of control of self at the same time as keeping the person with dementia central to the care is a continuing and exhausting struggle. However, it can be seen from the data that feelings and relationships can be supported and developed throughout and beyond the caring trajectory.

Entwined into the ebb and flow of the typology of caring relationships: recognising (1); transforming (2); stabilising (3); and moving on (4) are the very poignant practical interventions that can have a considerable effect on the life of a carer. Without timely information and knowledge these seemingly inexpensive and simple interventions can be missed. The continuity of carer relationships are central to these interventions occurring, as

they are often required without the carer knowing or being aware of how they can support the emotional relationship they have with the person with dementia. For example accessing the correct dietary advice, information about the diagnosis and accessing local services. From the data I can observe that timely interventions of this nature can provide a feeling of value to the caring role and can be likened to recovery. Recovery is a deeply personal unique process of changing one's attitudes, values, feelings, goals, skills and role(s). In this context it is a way of being able to continue or develop a new meaning to one's life, moving beyond the effects of mental illness. Recovery is not about removing the problem, illness, or caring role. It is about transcending to a different set of relationships and practical skills. It does not remove or change the fact that the experience has occurred, or can be still present and that the person's life is changed forever.

The findings in this study show that by having family and/or professional support to seek stabilisation of their relationships, a process of moving on can be achieved. They may seem like small steps but they require recognition and expertise on part of the carer. Carer A4 1/6 illustrates how her intimate relationship with her husband through touch providing a recognition of their relationship to their day to day life. Carer A3 6/6 illustrates with the support of his wider family he is able to achieve a close and stable relationship with his father and A7 3/6 illustrates with a picture her mother painted achieving new skills with the support of care home staff.

Nolan *et. al.*, (1996) and Sheard (2004a) suggest that relationships should be a platform for intervention to be built upon by health and social care workers, and Clarke (1999) recognises carer's expertise highlighting the tension that can exist between carer and professional who are entering the relationship with very different knowledge basis. The carer is the expert

about the ‘individual’ (person with dementia) and the professional is an ‘expert’ in knowing about and managing the disease, findings that this study supports.

## **Summary**

Relationships with the person with dementia are more often long standing relationships with a husband, wife or daughter, son etc. They are relationships that have developed over long periods of time in some cases over fifty years. Loneliness played a large part in the emotional feelings for the person with dementia. The carers participating in this study often felt very alone. A1 described how over a period of three years he became isolated and struggled with his relationship with his wife who he was finding difficult to recognise. He had become immersed in the day to day practicalities of their day, shutting out the more painful and difficult associations with the changing relationship between him and his wife. He felt guilty as he was no longer able to maintain the promises that he had made to his wife in earlier years. Being introduced to an Admiral Nurse relieved some of the pressure and gave him someone with a level of knowledge and skill to support his feelings and discuss a direction for the future that would be acceptable for both him and his wife.

The findings in the destiny stage of the 4 ‘D’ cycle have highlighted the way that carers strive for a sense of self within a complex caring role. Some carers were more successful in their attempts to do this than others due to those complexities. There is a complex interaction between the carer and the person with dementia and the people that support them has a powerful influence on how the caring role is supported and maintained. This is represented by the conceptual model of how Admiral Nurse principles and values support the role that has been presented in this chapter.

To live an active inclusive life that provides a sense of self carer's needs have to be recognised and the strategies that they devise must be supported by others. This does require the re-thinking of the notion that by meeting the needs of the person with dementia the needs of the carer will be met. This is only the foundation on which a carer can build the rest of their lives, which they can build on to live yet a different life, a life that they value.

*'I am me. I want to be recognised and listened to. I am not anonymous; I want to maintain my individuality. I want to build an honest and trusted relationship with an Admiral Nurse. I know my wife/husband/person I care for better than anyone professional. The physical and emotional care of the person I care for requires nurturing and understanding in the wider context of dementia.'*

(Provocative proposition – meeting the needs of the carer, focus group 3).

In Chapter 8 the 'energy' of the appreciative inquiry moves from the design stage towards planning implications for practice to realise the provocative propositions. This means reflecting on previous actions (findings) and articulating specific actions and activities for the future (Reed 2007). Completing an appreciative inquiry 4 'D' cycle not only facilitates development of plans for change but influences the future impacting the future beyond this thesis (Reed 2007). Chapter 8 provides a reflection of the research journey and implications for the future of Admiral Nurse practice.

## **Chapter 8**

### **Reflections on the Research Journey**

I began this study by giving a reflexive account of my personal and practice experiences. I was motivated to complete this study to observe a better understanding of what the meaning of family-centred Admiral Nursing is to carers.

The stories, photographs and narrative that have been explored portray the unique ways in which carers identify a typology of caring relationships: recognising (1); transforming (2); stabilising (3); and moving on (4). They are intimate stories about symbolic family interaction, friendship, grief and loneliness, achieving personal developments of self and relationships, fear of being able to cope with caring for a person with dementia, seeking ways to manage difficult symptoms, a working life, family and wider relationships along with struggles and accomplishments to retain their personhood. A typology of caring relationship were identified within the stories, recognising (1); transforming (2); stabilising (3); and moving on (4). The Admiral Nurse principles: Admiral Nurse attributes (1); meeting the needs of the carer (2); knowledge and skills (3) and working with organisations (4), and values have developed alongside these stories indicating that Admiral Nurse practice is valued for four core principles skills (personal and professional). Skills included; attributes (1); meeting the needs of the carer (2); knowledge and skills (3) and working with organisations (4). Each principle is underpinned by a set of values that include partnership, flexibility, empowerment, trust, honesty, continuity, negotiation, empathy and flexibility (Figure 9). This inquiry was designed with the explicit aim to meet with carers to develop a shared understanding of what the meaning of a family-centred approach. At the same time the

inquiry gained an explicit understanding of the Admiral Nurse principles and values that underpin the clinical practice of Admiral Nurses.

The final chapter in this thesis reflects on the meanings and implications of this inquiry, and begins to pull together some of the strands that have informed the thesis. In addition it reflects upon theoretical, methodological and policy/practice issues that are raised. The chapter commences with an examination of how carers come to care and the ways that the Admiral Nurse supports a carer to maintain their personhood during the trajectory of their caring role.

### **Making the Choice to Care**

Being identified as a carer is often a manifestation of many months or even years of anxiety about the cared for. The transition from, for example wife, husband, daughter and son can itself be a long process of elimination, anxiety of the unknown and juggling changing roles and emotions. The findings of this study have further identified that a carer's journey is not an easy one (Zarit and Zarit 1982; Zarit *et. al.* 1985; 1987; Perring *et. al.* 1990; Brooker 1991; Twigg and Atkin 1994; Nolan *et. al.* 1996; Clarke 1999; Maas *et. al.* 2004; Hellstrom *et. al.* 2005; Chene 2006; Daff *et. al.* 2006). The way a carer manages and is supported in their relationships during their caring role is not straightforward and continues well after the person with dementia is placed in a care home or has died.

There are significant times or emotional peaks when the carer seeks emotional and practical support. This happens namely at point of diagnosis, introduction to services, moving to another living environment and death of the person with dementia. Expectations of support from family and friends are reviewed and refined by the carer as the caring role progresses;

making attempts to successfully manage the complexity of their relational roles whilst keeping the person with dementia as their focus (see Chapters 6 and 7). The recognition, transformation and stability of their relationships influence how they manage their own feelings of value and wellbeing. Being successful in this highly complex situation is dependent on the changing symptoms and physical health of the carer and the person with dementia, the development of different facets of relationships with family members and friends, access to information and services and the ability to make and act on their choices.

However, carers do have physical, emotional and organisational constraints that limit what they can do. Yet they want recognition of their skill and knowledge about the person with dementia and what they can do to be valued and recognised. Although carers experience limitations, they develop a range of coping and management strategies with the aim of meeting the needs of the person with dementia as well as other significant family members. Where they are able to implement these strategies alone or with support, they reconstruct their lives as primarily a carer, with former relationships going through relational transitions and periods of stabilisation as illustrated in Chapters 6 and 7. This is a dynamic process often without a conclusion for many years.

Interpretation of the carers' stories in this thesis suggests that carers can maintain their caring role for longer if they can access timely and flexible support. In other words support systems/services are required to be accessible, maintain continuity, be knowledgeable and value the contribution the carer makes to the transformation of relationships when supporting the person they care for. This has been described throughout this thesis as 'caring relationships'.

The evidence suggests that carers can maintain a sense of wellbeing and value about themselves whilst they reconstruct their lives as carers. The conceptual model presented in Chapter 7 of carers ‘caring relationships’ portrays the complexity of emotional changes a carer experiences throughout their caring role. This model offers an explanation for the observation that carers are constantly transforming and striving to stabilise their relationships across a whole complex set of situations throughout the time the person with dementia is alive and sometimes beyond.

The carers in this study were very specific about wanting to have access to an Admiral Nurse throughout their trajectory of care and beyond. This held for them the possibility of retaining their own personhood, and stabilising their relationships and feelings of wellbeing and value. This is an alternative to a life of stress, burden and decline of mental and physical health. Carers consider that their common concern of being able to receive support of their ‘caring relationships’ in a way that reinstates and/or supports their personhood during the sometimes many years of their caring experience.

## **The Role of the Admiral Nurse**

The understanding that emerges from this study of how carers of people with dementia stabilise their relationships to enable them to continue to care resonates with and challenges different theoretical perspectives across many disciplines including nursing, social work, psychology and social policy. There are various possible contributions this study can make to these disciplines by adding to existing bodies of literature and participating in professional and academic debate. The contributions are discussed below in the context of the four identified principles and underlying values of Admiral Nurse practice.

## **Admiral Nurse attributes**

The carers who participated in this study articulated a need for a support service that prioritises relationships and care in family life. In situations where the carer was introduced to a service, it was primarily to meet the needs of the person with dementia. The professionals involved in the services were understandably required to meet those needs which at times were detrimental to the carer's health and wellbeing. For example A4 and A6 were both managing highly complex care situations and were offered services for the person they were caring for, but their own needs of recognising and transforming the relationships with their respective husbands when unmet caused great distress and emotional burden (Zarit and Zarit 1982; Zarit *et. al.* 1985; 1987; Pearlin 1990). In A4's case she preferred not to receive the service whilst trying to balance these feelings. The overwhelming consensus was that the person delivering the service should have personal attributes that include friendliness, trustworthiness, they are caring, have shared or flexible values, are flexible and have a commitment to their role (Lambert *et. al.* 2007).

Reconceptualising the status of the carer as a person who happens to be a carer focuses the attention on supporting the stabilisation of their relationships rather than merely living to care. The Admiral Nurse who has attained a set of attributes to support their practice has implications across disciplines. Learning and development in a professional capacity spans the course of a career, and Admiral Nurses bring attributes with them to their role. What differs is the way that Admiral Nurses are valued and how they value their ongoing practice development and supervision supported by the charity *for dementia*.

## **Meeting the needs of the carer**

Meeting the needs of the carer has been under much debate and scrutiny in the last decade. There does however remain much variation and ambiguity about the status of the carer within health, social and voluntary care settings. A carer is not a patient or client and does not necessarily have an identified health or social care need that is recognised by these statutory bodies. The well intentioned policies of the last ten years (DH 1999; DH 2000; DH 2004; DH 2007; DH 2009) have come some way in trying to provide statutory support for carers without identifying how it should be delivered or who by. The predominant model of support for carers in England is one of social support with little regard given to the relational changes that this study identifies. There is often confusion about who is receiving the care provided and on what premise, for example A4 found professionals entering her house to provide personal care for her husband an intrusion into the personal and intimate relationship and therefore refused it. A4 required support to stabilise her relationship with her husband so that she could value the caring role she was in. Without this she became increasingly isolated and stressed.

Within the Admiral Nurse model the carer is valued as a person, retaining the potential to live their life the way they want to, with the flexibility, continuity, partnership, honesty and trust that they require to address their emotional and practical needs (Friedemann 1989; Whyte 1997; Franck and Callery 2004 ).

## ***Knowledge and skills***

The recently published Living well with dementia – A National Strategy (DH 2009 p.49) states that,

*“Carers are the most important resource available for people with dementia”.*

The strategy sets out guidelines for practice that should include the provisions of the Carer's Strategy (DH 1999) of ensuring that every carer receives an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of people with dementia. It goes on to state that all health and social care staff involved in the care of people with dementia should have the necessary skills to provide the best quality care in the roles and settings where they work (DH 2009 p.63). Training was highlighted as a priority that ran across all the themes in the strategy.

An Admiral Nurse already has the basic, post registration experience and training in dementia care and complies with regular practice development and group supervision strategies supported by the charity *for dementia* (see Chapter 5). The carers in this study appraised highly the knowledge and skills of the Admiral Nurses they had worked with. They placed value on their professional knowledge of mental health, information gathering and sharing and supporting the needs of the person with dementia with the carer. The issue of creating and diffusing knowledge has previously been raised by Bradley (1996), the Admiral Nurses have a unique support system in *for dementia* in the way that they are provided with peer supervision and supported practice development. Should the Admiral Nurse aspire to the recommendations and forthcoming Nursing and Midwifery Committee Advanced Practice Register, they would be the only generic group of advanced practitioners in dementia care and their practice would truly reflect the importance that the National Strategy places on the role of a carer of a person with dementia.

However, there is much debate on the use of advanced practitioner and specialist nurse labels to areas of nursing (International Council of Nurses 2001; Nursing and Midwifery Council 2006; Mantzoukas & Watkinson 2007; Modernising Nursing Careers (MNC) 2008). The

report ‘Supporting the Developments of Advanced Nursing Practice: a toolkit approach,’ published in June 2008, provides practical and evidenced based guidance to advanced practice (MNC 2008). It acknowledges the confusion of the use in terms ‘specialist’ and ‘advanced’ and aims to provide both clarity and consistency to nurse development, deployment and service delivery. At time of writing this thesis it was aimed at engaging nurse practitioners in supporting career development and to link educational frameworks to the broader workforce issues. This will draw together existing and emerging work, to encourage consistency and to avoid duplication by aligning Agenda for Change job profiles, job descriptions, Knowledge and Skills outlines, agreed national competencies, educational preparation and credit to the Career Framework as well as examining the broader governance and regulation issues. The paper goes on to make recommendations about the role of the ‘specialist’ and ‘advanced’ nurse practitioner with clear pathways of development for each.

The description of the data from the questionnaire (Chapter 5) identified how Admiral Nursing has developed as a specialist role with an emerging advanced practitioner role. There is evidence of a likeness to the educational preparation, nature of practice and regulatory mechanisms discussed in the MNC report (2008).

Knowledge and skills can be applied to support a family-centred approach in a variety of ways; face to face, in groups, via telephone and email. The importance of receiving skilled facilitation has been highlighted by the carers throughout this thesis; therefore support should not necessarily be withdrawn following the completion of face to face interactions.

### **Working with organisations**

The ability to work collaboratively and across organisations requires considerable support and skills on part of the Admiral Nurse. The value of partnership working and the ability to empower not only carers but other professionals have been highlighted as important in the

findings of this study. It is an element of the family-centred care approaches discussed in Chapter 3. Friedemann (1989) discussed that is basic to a family-centred approach. The first is the focus on health rather than on pathology, this is particularly relevant for the Admiral Nurse whose focus is primarily on the carer who is not a ‘patient’. Admiral Nursing does not need to be driven by pathology; indeed the findings of this study support this. It just needs to be driven by genuine acceptance and genuine concern for the carer. Admiral Nursing must consist of actions that reinforce the carers’ and, where appropriate the wider families’ strengths to instigate stabilisation of the carers’ relationships. In order to practice with a family-centred approach it is essential to work with other organisations across health, social care and voluntary sectors. The sharing of information and good communication are essential for quality care and this has been highlighted as a value of Admiral Nursing throughout this study.

## **Summary**

I began this study by asking, what is the meaning of family-centred Admiral Nursing to carers? As the inquiry has developed it has become clear that although there are close links with the principles of family-centred approaches discussed in Chapter 3 of this thesis the approach that has emerged has been one that is based on the typology of caring relationships. The four principles: Admiral Nurse attributes (1); meeting the needs of the carer (2); knowledge and skills (3) and working with organisations (4) and underlying values have similarities to the discussed literature in that they support partnership working with the carer and drive care to a model of empowerment and enablement. The findings differ in that they do not provide a formal framework for Admiral Nurse practice but an approach to practice that is based on the theoretical understanding of the typologies of caring relationships: recognising (1); transforming (2); stabilising (3); and moving on (4).

## **Reflections of using appreciative inquiry as a research methodology**

The work in this thesis demonstrates the value and power of appreciative inquiry to generate and contribute to the embedding of theory into future practice and policy. It is recommended to other researchers to recognise its worth as a qualitative methodology in health and social care. I will now develop this point.

Starting out as a student researcher with a clinical background in dementia care nursing I began my research journey by struggling with the traditional methodologies of approaching data collection by thinking about researching a ‘problem’. Dementia struggles with the stigma of a mental health problem with cognitive deterioration, meaning loss of self and one’s dignity. Adopting an affirmative approach to the study sat well with my expertise in clinical practice. It helped develop my confidence as a novice to research and gave me a way of developing my research questions.

The participants in the study were a wide range of people with different skills, experiences and knowledge, all of whom were experienced in managing and coping with day to day problems in their personal and working lives. I was therefore surprised when the use of appreciative inquiry did not quite receive the accolade I thought it would (Chaffee 2006). The participants were unsure when I asked them to think affirmatively, some saying they did not think they would be able to do that. This returned me again to the issue of dispelling the stigma of dementia. However, these feelings were not to be ignored and required addressing within the data collection process as suggested by Carter (2006) and Reed (2007). Participants were invited to tell their ‘story’ first, I listened and offered an empathic ear. As the reader has seen, the initial stories held a whole host of distressed emotion and in some cases despair at the situation the carers found themselves in. However, we continued together

and with support the participants were gradually able to focus on the affirmative with, in some cases, very personal positive effects. The participant who was not well enough to participate in the telephone interviews felt so inspired from contributing to the photographs and narratives she has gone on to use her photographs as a tool to speak to groups about her experiences as a carer. She has also registered to study for a degree with the Open University. I would, however, advocate the importance of listening to the ‘problems’ that the stories hold in appreciative inquiry as they are rich sources for data collection. Every story should be valued for its individual nature. Reed, (2007) raises the issue of not ignoring the problems but of working with them to reach an affirmative conclusion, my experience in the discovery stage of this thesis confirms these findings. Once the problems were acknowledged and validated the participants were able to move their discussion forward to explore the affirmative content of their experiences. The use of appreciative inquiry therefore became an interesting way of beginning to uncover periods of wellbeing and value in carer’s experiences of caring for a person with dementia and clarifying how wellbeing is sustained throughout the caring trajectory.

Importantly the use of creativity that appreciative inquiry allows contributes towards the development of a new trend in data collection and analysis in qualitative research where visual representations and collaborative approaches define the research experience. Within this study, representations of reality can be difficult to interpret without the meaning of that experience communicated (in this instance) by the carer. For example, in Chapter 6 carer’s A4 (2/6) photograph shows an entry door with latches and bolts that could have been interpreted by professional staff as an expression of isolation and of being ‘shut away’ from the wider world. This was far from the case and highlights the importance of gathering biographical information and not making ‘snap judgements’. Arguably, it is for this reason

that authors such as Harrison (2002); Chaplin (1994) and Harper (1996) have found the absence of the use of visual methodologies in social research surprising, as they often unlock private thoughts in a sensitive way.

One of the key factors for using appreciative inquiry as a research methodology was its collaborative nature. Appreciative inquiry was built as a methodology for organisational change (Cooperrider and Srivasta 1987), my experience reflects the fact that people are individuals and do not easily fit into an organisational framework this is one of the themes that arises from the data, everyone is unique with individual experiences, relationships, hopes and wishes (Reed 2007). Although I have spoken earlier in this thesis about appreciative inquiry being a reasonably new approach to research it is only recently that the worlds of organisational change and research have collided (Carter 2006). As I have emphasised throughout this thesis appreciative inquiry is about studying and exploring what is good, strong, already working and being achieved. It was for this reason that I made adaptations to the interview process in the discovery phase. Asking for carers to volunteer for three focus groups would have been burdensome and difficult for them excluding many from contributing to the study. By making the telephone interviews one to one opportunities to contribute I was able to widen the contributory nature of the study. Carter (2006) adopted a similar approach with his study with ‘enhancing best practice for children with complex needs’. People with dementia are increasingly being invited to participate in research and service design and I was very adamant that they should have a voice in this study. By using creative methods within the appreciative inquiry methodology I was able to offer, not just people with dementia, but everyone different methods in which they could contribute to the data collection.

Collecting the data in the focus groups was a different experience as a researcher. The data were less personal and the approach, although flexible to allow for different cognitive abilities, was rather more formal. The mind mapping allowed for the creativity of appreciative inquiry and stimulated questions, discussions and themes amongst each of the groups. The atmosphere of each group was relaxed and inclusive. Participants did however need to keep reminding themselves about the affirmative focus of the questions, drawing themselves back to values rather than the ‘problems’ encountered. Facilitating the groups to recognise ‘their value’ was extremely rewarding and generated huge amounts of energy, raising morale and a real feeling of ‘we can influence this piece of research’. For some participants they contributed to changes in feelings of self value and worth.

On discussing an appreciative inquiry approach with my supervision team and other research students I realise that my reflections are not different to others when using other methodologies in the field of the social sciences. I have however, kept the participation of people in this study as the highest priority and would not wish to lose the emotional feelings of each participant’s contribution to this thesis.

## **Summary**

Much has been learned about what carers value about themselves and working with an Admiral Nurse. The overriding conclusion that can be drawn is that carers are constantly trying to stabilise their lives throughout their caring role and often beyond. Some were able to achieve this to a greater or lesser extent within their own family unit, and the conceptual model of the typology of caring relationships that has been developed in this thesis provides a framework to depict the complexity of the shape the relational journey a carer takes when caring for a person with dementia. An inherent feature of the model is recognition that carers

are individuals that require recognition of ‘self’ and this contributes to the growing body of literature that points to a relational approach to care of people with dementia.

Whilst this interpretation of carer relationships makes no claim to fully represent the experiences of all carers of people with dementia, the understanding of value and carers’ selfhood that have been developed through this study does offer a family-centred approach to how Admiral Nurses can support carers of people with dementia. This approach to supporting carers provides an alternative to a caring role of stress and burden to one of value and relational stabilisation. This image provides a view of caring that is grounded in the views of carers.

As my research journey draws to a close a new journey is just beginning for me as it is for many of the carers who were part of this study. I have learnt a lot from the people who I have met along the way and who have stimulated me to find out more of what exists. I now know that Admiral Nurses are valued for their attitudes and attributes and that there is a different approach to nurse practice that can provide care and support that includes a family-centred approach. With this knowledge new challenges arise that will require commitment from Admiral Nurses and their stakeholders to realise the potential of Admiral Nursing in supporting carers of people with dementia.

Finally this thesis draws to a close with thanks to all the people that I have met and have participated with me along my research journey. Some are no longer with us yet their stories and experiences live on beyond them. These stories are available for others to see the world in which carers wish to be valued and supported.

**Appendix 1 University of Northumbria approval letter and National Research Ethics Committee approval letter**



School of Health, Community and Education Studies  
Postgraduate and Research Support Unit  
Room H210  
Coach Lane Campus East  
Newcastle upon Tyne NE7 7XA

Tel: 0191 215 6276  
Fax: 0191 215 6605  
[lorna.kennedy@unn.ac.uk](mailto:lorna.kennedy@unn.ac.uk)

20 September 2006

Penelope Hibberd  
24 Rye Lane  
OTFORD  
Kent  
TN14 5LU

Dear Penelope

**School of HCES Research Ethics Sub Committee**

**Title: Family Centred Admiral Nursing: re-conceptualising practice values.**

Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and that the University Policies on Ethics and Consent are followed.

You may now also proceed with your application (if applicable) to:

- NHS organisations for Trust approval where appropriate.
- Local Research Ethics Committee (LREC), or Multi-Centred Research Ethics Committee (MREC). [Please forward a copy of this letter where appropriate plus the peer reviewers comments and your response to those comments.]

**Please ensure that the contact details and statement on funding are reviewed by your new supervision team.**

**IMPORTANT: PLEASE FORWARD A COPY OF YOUR LREC/MREC APPROVAL LETTER TO THE ABOVE ADDRESS.**

- Please also agree honorary contract(s) with Trusts where appropriate. **Please forward a copy of any agreed honorary contracts to the above address.** Note that occupational health and criminal records bureau clearance may also be required.
- The above Committee would be willing to forward the independent peer review form to relevant R&D NHS Trusts/LREC/MREC upon receipt of a signed request from yourself.

**All researchers must also notify this office of the following:**

- Commencement and completion of the study;
- Any significant changes to the study design;
- Any adverse effects on participants or staff;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

A handwritten signature in black ink, appearing to read "Charlotte Clarke".

Professor Charlotte Clarke  
Associate Dean (Research)



## National Research Ethics Service

### Essex 1 Research Ethics Committee

(Note: ESSEX 1 and ESSEX 2 REC's are an amalgamation of

South Essex, North & Mid Essex and West Essex REC's)

Level 9 Terminus House The High  
Harlow Essex CM20 1XA

Tel/Fax: 01279 694917

Email: [liz.wrighton@eoe.nhs.uk](mailto:liz.wrighton@eoe.nhs.uk)

13 April 2007

Mrs Penelope A. Hibberd  
Senior Lecturer  
Northumbria University  
24 Rye Lane  
Otford  
Kent TN14 5LU

Dear Mrs Hibberd

**Full title of study:** Family-centred Admiral Nursing: Re-conceptualising practice values  
**REC reference number:** 06/Q0301/89

Thank you for your letter of 10 April 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

#### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application: A39 only		20 November 2006

<i>Covering Letter</i>		<i>23 November 2006</i>
Summary/Synopsis	01	01 September 2006
Letter from Sponsor : RCN & NHS Trust Honorary Contract		23 March 2007
Letter of invitation to participant : Invitation to become a member of a carers research reference group - appendix 3	03	15 February 2007
GP/Consultant Information Sheets Appendix - 21	01	15 February 2007
Participant Information Sheet	2	09 January 2007
Participant Consent Form: Testing of toolkit - appendix 22	02	20 November 2006
Participant Consent Form: Stakeholders Consent to Participate in Focus Groups/Telephone Interviews	4	10 April 2007
Participant Consent Form: People with dementia - appendix 13	4	10 April 2007
Participant Consent Form: Consent to Participate in Focus Groups (Carers) - appx 11	4	10 April 2007
Participant Consent Form: Admiral Nurse Team Consent for Participating in Questionnaires and Focus Groups and Telephone Interviews - appx 9	4	10 April 2007
Participant Consent Form: Admiral Nurse Consent to Participate in Focus Groups - appx 7	4	10 April 2007
Participant Consent Form: Reference Group Practice Development Lead Nurse & Retired Admiral Nurse - appx 27	4	10 April 2007
Participant Consent Form: Service managers consent to participant in focus groups/telephone interviews - appendix 25	3	10 April 2007
Participant Consent Form: Focus Groups Consent to Participating in the Development of Carer Competencies - appx 24	4	10 April 2007
Participant Consent Form: Telephone Interviews - appx 18	4	10 April 2007
Response to Request for Further Information		05 March 2007
Response to Request for Further Information		10 April 2007
cv for John Keady		01 May 2006
Letter of invitation to participants - testing of toolkit letter of information - appendix 21	01	20 November 2006
Statement of indemnity arrangements - letter from RCN & copy of NHS Trust Honorary Contract		03 January 2007
Family competency framework letter - appendix 23	3	10 April 2007
Non-validated questionnaire - Admiral Nurse questionnaire - appendix 5	3	10 April 2007
Telephone interview letter of information - appendix 19	3	10 April 2007
Letter of invitation to participants - carers letter invite to focus groups - appendix 10	02	15 February 2007
Letter of invitation to participants - admiral nurse letter - focus groups -appendix 6	02	15 February 2007
Letter of invitation to participants - invite to complete admiral nurse questionnaire - appendix 4	02	15 February 2007
People with dementia letter of thanks - appendix 15	02	15 February 2007
Letter practice development lead nurse/retired admiral nurse consultancy role - appendix 26	02	15 February 2007
The NMC code of professional conduct		
Power point presentation - appendix 2	02	16 February 2007
Letter to stakeholders focus groups - appendix 16	02	15 February 2007
Interview schedules or topic guides for participants - topic guide focus groups & telephone interviews - appendix 20	02	15 February 2007

Confirmation of funding		08 February 2007
Letter service manager focus group - appendix 08	02	15 February 2007
Request to attend meeting carers & people with dementia - appendix 12	02	15 February 2007
Request to attend meeting carers & people with dementia - appendix 13a	02	15 February 2007
People with dementia letter focus groups - appendix 14	02	15 February 2007
Supervisor cv		

### R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final approval from the R&D office before commencing any research procedures.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q0301/89

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



P  
Mr H Bliss  
Chairman

Enclosures: Standard approval conditions

Copy to: Professor Charlotte Clarke  
 Northumbria University  
 School of Health, Community & Education Studies,  
 Postgraduate & Research Support Unit, Room H210  
 Coach Lane Campus East, Newcastle-upon-Tyne  
 NE7 7XA

**Appendix 2    Research and development ethical approval letters**

Governance Department  
220 The Bungalow  
Charles Hastings Way  
Worcester  
WR5 1DD

P: 01905 733443 ext. 37905

Penny Hibberd  
Admiral Nurse/Senior Lecturer  
The Department of Social Work, Community and Mental Health  
Faculty of Health and Social Care  
Canterbury Christ Church University  
North Holmes Road  
Canterbury  
Kent  
CT1 1QU

13<sup>th</sup> February 2008

Research Log Ref. No: R07:45

Dear Penny,

Thank you for your Research Proposal entitled 'Family-centred Admiral Nursing: Re-conceptualising practice values'. I take great pleasure in informing you that your proposal was granted approval by the Audit and Research Group on behalf of Worcestershire Mental Health Partnership NHS Trust, on 27<sup>th</sup> September 2007.

Please accept this letter as official confirmation of Trust Approval.

I should like to take this opportunity to wish you well with your research, and look forward to seeing your final report.

If I can be of further assistance please do not hesitate in contacting me.

Yours sincerely,



*Sam Whithby*  
Acting Audit & Research Manager

R&D Unit, BSMHT  
Radclyffe House  
66/68 Hagley Road  
Edgbaston  
Birmingham  
B16 8PF  
Tel: 0121 678 4326  
Fax: 0121 678 4319

Ms Penelope Hibberd  
24 Rye Lane  
Otford  
Kent  
Sevenoaks  
TN14 5LU

Dear Ms Hibberd,

**Re: "Family Centred Admiral Nursing: Re-Conceptualising practice values".**

Thank you for returning your completed Trust Research Application Form for the above project. This research was approved by the Director of Research & Development and we have received notification of a favourable ethical opinion. You may therefore commence the work.

Please note that the Trust's approval of this research is given on the understanding that you are aware of and will fulfil your responsibilities under the Department of Health's *Research Governance Framework for Health and Social Care*, including complying with any monitoring/auditing of research undertaken by the Research & Development Unit.

Please do not hesitate in contacting the Research & Development Unit should you require any advice or support on any aspect of your project. When contacting us it would be helpful to quote our reference number for this project: **NRR 847**

Yours sincerely,

*Theresa Morton*

Theresa Morton  
Research Manager

R & D DEPARTMENT  
ST. ANN'S HOSPITAL  
ST. ANN'S ROAD  
LONDON N15 3TH

E-mail: research.department@beh-mht.nhs.uk  
Direct Line: 020 8442 6503

06 July 2007

Mrs Penelope Hibberd  
Admiral Nurse /Senior Lecturer  
24 Rye Lane  
Otford, Sevenoaks  
Kent  
TN14 5LU

Dear Mrs Hibberd,

Title of Study: **Family-centred Admiral Nursing: Re-conceptualising practice values**

REC reference number: **06/Q0301/89**

I am pleased to note that you have received the favourable opinion of the Research Ethics Committee for your study.

All projects must be registered with the Research Department if they use patients, staff, records, facilities or other resources of the Barnet, Enfield and Haringey NHS Mental Health Trust.

The R&D Department on behalf of Barnet, Enfield and Haringey NHS Mental Health Trust is therefore able to grant approval for your research to begin, based on your research application and proposal reviewed by the ethics committee. Please note this is subject to any conditions set out in their letter dated **13 April 2007**. Should you fail to adhere to these conditions or deviate from the protocol reviewed by the ethics committee, then this approval would become void. The approval is also subject to your consent for information to be extracted from your project registration form for inclusion in NHS project registration/management databases and, where appropriate, the National Research Register.

Permission to conduct research is also conditional on the research being conducted in accordance with the Department of Health Research Governance Framework for Health and Social Care\*:

- Appendix A to this letter outlines responsibilities of principal investigators
- Appendix B details the research governance responsibilities for other researchers. It also outlines the duties of all researchers under the Health and Safety at Work Act 1974. Principal investigators should disseminate the contents of Appendix B to all those in their research teams.

It is required that all researchers submit a copy of their report on completion and details on the progress of the study will be required periodically for longer projects. Copies of all publications emanating from the study should also be submitted to the R&D Department.

Furthermore, all publications must contain the following acknowledgement.

*"This work was undertaken with the support of Barnet, Enfield and Haringey NHS Mental Health Trust, who received "funding" from the NHS Executive; the views expressed in this publication are those of the authors and not necessarily those of the NHS Executive".*

*"a proportion of funding" where the research is also supported by an external funding body; "funding" where no external funding has been obtained.*

Best wishes and every success with the study.

Yours sincerely,



Dr Gerard Leavey  
Assistant Director R & D

\*Further information on research governance can be obtained on the DH web pages at <http://www.doh.gov.uk/research/>

14 May 2007

Mrs P Hibberd  
24 Rye Lane  
Otford  
Sevenoaks  
Kent  
TN14 5LU

Research & Development Office  
Room 109, Harrop House  
Bury New Road  
Prestwich  
Manchester M25 3BL

Tel: 0161 772 3591/3954  
Fax: 0161 772 3550

Email: [kathryn.harney@bstmht.nhs.uk](mailto:kathryn.harney@bstmht.nhs.uk)  
[jennifer.higham@bstmht.nhs.uk](mailto:jennifer.higham@bstmht.nhs.uk)

Dear Mrs Hibberd

**Re: NHS Trust Approval to Proceed**

**Project Reference: bstmht 495**

**Project Title : Family-centred Admiral Nursing: Re-conceptualising practice values**

I am pleased to inform you that the above project was approved at the Research Governance Group meeting. Trust R&D approval covers all locations within the Trust, however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers.

Please take the time to read through this letter carefully and contact the R&D Office should you require any further information. You may need this letter as proof of your approval.

**Honorary Research Contracts (HRC)**

All researchers with no contractual relationship with any NHS body, who are to interact with NHS patients in a way that directly affects the quality of their care, should hold honorary NHS contracts. For more information on whether you or any of your research team will require an HRC please liaise with the R&D office. It is your responsibility to inform us if any of your team do not hold NHS contracts.

**Research Governance**

The Research Governance Sponsor for this study is Northumbria University. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at <http://www.dh.gov.uk> website then use the DH search facility.

For further information or guidance concerning your responsibilities, please contact your research governance sponsor.

## **Risk and Incident Reporting**

Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact the R&D Office for support and guidance.

## **Confidentiality and Information Governance**

All personnel working on this project are bound by a duty of confidentiality. All material accessed in the Trust must be treated in accordance with the Data Protection Act (1998).

## **NRR**

We are required by DH to register all non-commercial research carried out within the Trust on the National Research Register (NRR). These details are published on the internet at <http://www.nrr.nhs.uk/>.

## **Protocol / Substantial Amendments**

You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

## **Monitoring / Participant Recruitment Details**

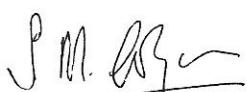
You will be required to produce a short electronic progress report annually and at completion. Please make sure that you will be able to supply an accurate account of the recruitment targets and numbers recruited for this Trust. Reporting is kept to a minimum; however, if you fail to supply the information requested, the Trust may withdraw approval.

## **Final Reports**

At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the Trust intranet site to ensure findings are disseminated as widely as possible to stakeholders.

On behalf of this Trust, may I wish you every success with your research.

Yours sincerely



Dr Stephen Colgan  
Medical Director & Trust R&D Lead

cc : Research Governance Sponsor

18 July 2007

Penny Hibberd  
Admiral Nurse Lecturer/Practitioner  
PhD Student  
24 Rye Lane  
OTFORD  
Sevenoaks, Kent  
TN14 5LU

Kent Forensic Psychiatry Service  
Trevor Gibbens Unit  
Hermitage Lane  
Maidstone  
Kent  
ME16 9PH

Tel : 01622 723143  
Fax: 01622 723147

Dear Penny

**Re: Family centred Admiral Nursing project**

Your project has now been approved by the R&D committee. I would be grateful if you could sign the enclosed form and return it to me at the Trevor Gibbens Unit immediately.

Good luck with your research.

Best wishes,

Yours sincerely

*A. Lockerbie*

*AL* Dr Lona Lockerbie  
Deputy Chair - Research Committee

Enc



 You replied on 5/11/2007 8:40 AM.

This message was sent with high importance.

**Hibberd, Penny (penny.hibberd@canterbury.ac.uk)**

**From:** Gibson Beverley [Beverley.Gibson@lancashirecare.nhs.uk] **Sent:** Thu 5/10/2007 5:05 PM

**To:** Hibberd, Penny (penny.hibberd@canterbury.ac.uk)

**Cc:** Worrell Louise

**Subject:** RE: Family-centred Admiral Nursing: Re-conceptualising practice values

**Attachments:**

Dear Penny

Thank you for the email. Coming back to you whether Lancashire Care NHS Trust R&D approval is required, I have spoken to the R&D manager and we agree that you don't need our trusts approval, however we would prefer you not to conduct a telephone interview whilst the participants are on work time.

If you have any queries please do not hesitate to contact me

Kind regards  
Beverley

-----Original Message-----

From: penny.hibberd@canterbury.ac.uk

[<mailto:penny.hibberd@canterbury.ac.uk>]

Sent: 08 May 2007 13:17

To: Gibson Beverley

Subject: RE: Family-centred Admiral Nursing: Re-conceptualising practice values

Dear Beverley,

Thank you for your email.

The nurses will be involved on the Hulton Hospital site as this is where they meet regularly for practice development and supervision. The stakeholders will be invited to join a group either on this site or at the charity for dementia headquarters in London (this is to maximise the numbers for a viable group).

Telephone interviews will be offered to those who are unable or would prefer not to join a focus group. It will be the participants choice where they take the phone call for the telephone interview. It will be taken as an incoming call as I will meet the costs for the call.

Please let me know if you require any further information or I am available on 01959 524048 this afternoon.

Regards  
Penny

Penny Hibberd  
Admiral Nurse/Senior Lecturer  
The Department of Social Work, Community and Mental Health  
Faculty of Health and Social Care  
Canterbury Christ Church University  
North Holmes Road  
Canterbury  
Kent CT1 1QU

Penelope Hibberd  
Senior Lecturer  
Northumbria University  
24 Rye Lane  
Otford  
Kent  
TN14 5LU

22/06/2007

### **Trust Approval to Proceed**

Dear Penelope

#### **Re: NHS Trust Approval to Proceed**

**Project Reference: 0584**

**Project Title : Family-centred Admiral Nursing**

I am pleased to inform you that the above project has been discussed and approved. Your project was approved at our R&D approval meeting on 19/06/07. Your Trust contact person will be Susan Ashcroft-Simpson the Lead at our Admiral Nursing Service, please contact Susan at;

Admiral Nurse Service  
C/o Community Securities  
6 Cambrian Street  
Beswick  
Manchester  
M11 3FY  
0161 275 9115

Please take the time to read through this letter carefully and contact me if you would like any further information. You may need this letter as proof of your approval.

#### **Honorary Research Contracts**

All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that directly affects the quality of their care, should hold honorary NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for*

*Health and Social Care, 2005).* For more information on whether you or any of your research team will require an HRC please liaise with this office. It is your responsibility to inform us if any of your team do not hold honorary NHS contracts.

### **Research Governance**

The Research Governance Sponsor for this study is *Northumbria University*. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at

[http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4108962&ch\\_k=Wde1Tv](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&ch_k=Wde1Tv)

For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

### **Risk and Incident Reporting**

Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

### **Confidentiality and Information Governance**

All personnel working on this project are bound by a duty of confidentiality. All material accessed in the trust must be treated in accordance with the Data Protection Act (1998). For good practice guidance on information governance contact us.

### **NRR <http://www.nrr.nhs.uk/>**

We are required by DH to report all non-commercial research carried out within the trust to the National Research Register (NRR). In order to comply, we will prepare a summary extracted from the information you have already provided to us. These details are published on the internet. If you wish to receive a copy of the NRR information for your study, please contact me.

### **Protocol / Substantial Amendments**

You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

### **Monitoring / Participant Recruitment Details**

You will be required to produce a short electronic progress report on completion or annually as a minimum. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust ( recruitment target, actual numbers recruited). To reduce bureaucracy,

progress reporting is kept to a minimum; however, if you fail to supply the information requested, the trust may withdraw approval.

### Final Reports

At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,

  
Deana Kelly  
Research & Development Coordinator

Research and Development Directorate  
Mascalls Park  
Mascalls Lane  
Brentwood  
Essex  
CM14 5HQ

Tel: 01277 302672  
Fax: 01277 302739

Monday, 04 June 2007

Mrs Penelope A. Hibberd  
PhD Student  
Northumbria University  
24 Rye Lane  
Otford  
Kent  
TN14 5LU

Dear Mrs Hibberd,

**RE: Family-centred Admiral Nursing: Re-conceptualising practice values.**

I am pleased to confirm that the above named project has been granted R&D approval and indemnity by Professor Orrell, Director of NELMHT Research and Development Department. Good luck with the project.

Yours sincerely,



Amy Bartlett  
R&D Acting Manager



North East Wales NHS Trust  
Internal Review Panel  
Clinical Audit/Research  
Effectiveness Department  
Wrexham Medical Institute,  
Croesnewydd Road,  
Technology Park, Wrexham.  
LL13 7YP  
Tel: 01978 291100 ext 7453

Our Ref JJ/jh/RP07/08/00 (please quote in all correspondence)

20<sup>th</sup> August 2007.

Private & Confidential  
Penny Hibberd  
Admiral Nurse/Senior lecturer  
The Department of Social Work Community and Mental Health  
Faculty of Health & Social Care, Canterbury Christ Church University  
North Holmes Road, Canterbury, KENT  
CT1 1QU.

Dear Ms Hibberd

RE: Family-centred Admiral Nursing: Re-conceptualising practice values

Thank you for submitting the above project for review by the North East Wales NHS Trust Internal Review Panel. This has been noted by the Internal Review Panel and it has been agreed that this project does not require full R&D review for you to undertake the project within the North East Wales Trust. However, this only applies to this Trust and if the project is to be considered in other Trusts in England and Wales you will need to apply to the relevant R & D Offices.

Yours sincerely

 Mrs Julie Jones  
Research & Audit Manager  
Clinical Audit / Research Effectiveness

# South West London and St.George's

Mental Health NHS Trust

## Research and Development

Penny Hibberd  
24 Rye Lane  
Otford  
Sevenoaks  
Kent TN14 5LU

**Director:** Professor Mohammed Abou-Saleh

HUNTER WING  
CRANMER TERRACE  
LONDON SW17 0RE

**R&D Co-ordinator:** Ms Enitan Eboda  
**Email:** [eeboda@sgul.ac.uk](mailto:eeboda@sgul.ac.uk)

Direct Line: 020 8725 3463/5718  
Fax: 020 8725 3538

18 July 2007

Dear Penny,

**Research Title:** Family-centred Admiral Nursing: Re-conceptualising practice values

**Project ID:** PF343

Following various discussions your project has now been approved. This letter ensures that you and the researchers holding a Trust/NHS contract are indemnified by the Trust under DoH HSG (96) 48 (**only for non-commercial research**). Under your contract of employment you are required to adhere to the Research Governance Framework and Trust research monitoring procedures.

In addition to ensuring that the dignity, safety and well-being of participants are given priority at all times by the research team, you need to ensure the following:

- **Patient contact:** Only trained or supervised researchers holding a Trust/NHS contract (honorary or full) are allowed to make contact with patients.
- **Informed consent:** is obtained by the lead or trained researcher according to the requirements of the ethics committee. The original signed consent form should be kept on file. Informed consent will be monitored by the Trust at intervals and you will be required to provide relevant information.
- **Data Protection:** All data involving patient data will remain anonymised, where possible, and held on protected systems so as not to compromise the Data Protection Act.
- **Adverse events reporting:** Adverse events or suspected misconduct must be reported to the R & D department, in conjunction with the Ethics committee.

Terms and conditions of Approval

- **Annual review:** An annual review form will be sent to you, which you will be required to complete and return to the R & D Department.
- **Closure Form:** On completion of your project a closure form will be sent to you (according to the end date specified on the R & D database), which needs to be returned to the R & D Department.
- **Publications:** Any publications will need to be reported to the R & D Department. This is vital in ensuring the quality and output of the research for your project and the Trust as a whole.

The R & D Department needs to be informed of any changes to the protocol such as patient recruitment, funding, etc. If any major changes are made to the protocol then this would need to go to the R & D Committee.

If you have any queries regarding the above points please contact Enitan Eboda, R&D Co-ordinator on 020 8725 3463 (St. George's), e-mail: [eeboda@sgul.ac.uk](mailto:eeboda@sgul.ac.uk).

Yours sincerely,



Professor Mohammed Abou-Saleh  
Chairman  
Research & Development Committee.



**C/o Warwickshire PCT**  
Westgate House, 21 Market Street  
Warwick, CV34 4DE  
DDI: 01926 493 491 ext 252  
[rd.office@swarkpct.nhs.uk](mailto:rd.office@swarkpct.nhs.uk)

Mrs Penelope Hibberd  
Senior Lecturer  
Northumbria University  
24 Rye Lane  
Otford  
Kent  
TN14 5LU

9 July 2007

ref: PAR150507

Dear Penny,

I am pleased to confirm that **Coventry & Warwickshire Partnership Trust** have reviewed the research entitled "Family-centred Admiral Nursing: Re-conceptualising practice values" and give approval for Admiral Nurses to be recruited into this study within the Trust on the following conditions.

1. Coventry & Warwickshire Partnership Trust suffers no costs as a result of this research being undertaken.
2. Northumbria University will provide professional liability for its staff undertaking this research, covering negligent harm related to protocol design. We appreciate this does not cover clinical negligence.

Your research has been entered into the Trust's Research database (if applicable this will be entered onto the National Research Register).

**Please reply to this letter confirming the expected start date and duration of the study.** As part of the Research Governance Framework it is important that the Trust is notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. We may also request brief updates of your progress from time to time, dependent on duration of the study. Similarly, if at anytime details relating to the research project or researcher change, the R&D department must be informed.

If you have any further questions regarding this or other research you may wish to undertake in the Trust please feel free to contact me again. The Trust wishes you success with your research.

Yours sincerely

A handwritten signature in black ink, appearing to read "Chris Beyer".

Chris Beyer

R&D Office – West Midlands South RM&G

6 August 2007

Ref no: HIBPC7001

Dear Mrs Hibberd

**Re: Family-centred Admiral Nursing: re-conceptualising practice values**

I am pleased to confirm that the above project has received Trust R&D approval, and you may now commence your research.

May I take the opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold a Trust/NHS contract (honorary or full) are allowed contact with Trust patients. If you do not hold a contract please contact the R&D Office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D Office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act.
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Adverse events:** adverse events or suspected misconduct should be reported to the R&D Office and the Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D Office.
- **Publications:** it is essential that you inform the R&D Office about any publications which result from your research.

We would like to wish you every success with your project.

Regards

**Maria Tsappis**  
Research Governance Co-ordinator

**Appendix 3 Consent form for people with dementia**



**Family-centred Admiral Nursing  
People with Dementia Consent to Participate in Focus Groups**

Lead Researcher: Penny Hibberd Admiral Nurse Lecturer/Practitioner PhD student

**Please initial each box**

1. I confirm that I have read and understand the information leaflet dated 09/01/2007 version 02 for the above study. I have had the opportunity to consider the information ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my Admiral Nurse Care (if applicable) or legal rights being affected.
3. I understand that the focus groups will be audio-taped and later transcribed by the lead researcher.
4. I understand that the transcriptions may be used at a later stage of the study for publication or for use in conference presentations.
5. I understand that photographs that are taken during the groups may be used at a later stage for conference publication or for use in conference presentations.
6. I understand that all participants will have the right to have direct quotations removed from the transcriptions.
  
7. I agree to my G.P. or Clinician being informed of my participation in the study.
  
8. I agree to take part in the above study.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of person taking consent  
(if different from the researcher)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature:

\_\_\_\_\_  
Date:



**Appendix 4 Consent form**

**Family-centred Admiral Nursing**

**Admiral Nurse Consent to Participate in Focus Groups**

Lead Researcher: Penny Hibberd Admiral Nurse Lecturer/Practitioner PhD student

Please initial each box:

1. I confirm that I have read and understand the information leaflet dated 09/01/2007 version 02 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that the focus groups/telephone interviews will be audio-taped and later transcribed by the lead researcher.
4. I understand that the transcriptions may be used at a later stage of the study for publication or for use in conference presentations.
5. I understand that photographs that are taken during the groups may be used at a later stage for conference publication or for use in conference presentations.
6. I understand that all participants will have the right to have direct quotations removed from the transcriptions.
7. I agree to take part in the above study.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of person taking consent  
*(If different from the researcher)*

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature:

\_\_\_\_\_  
Date:

*When completed, 1 for participant; 1 for researcher*

## Appendix 5 Participant information sheet



### Family-centred Admiral Nursing Participant Information Sheet

**This is an invitation to participate in my research study.**

#### About me:

My name is Penny Hibberd I am married with three grown up daughters. I have been a nurse since the 1970's in that time I have been part of many changes and gained much experience in community nursing with older people and with a Specialist Service for Carers. I have been an Admiral Nurse for the last seven years in Kent. Over the last three years I have combined my Admiral Nursing role with a Senior Lecturers role at Canterbury Christ Church University. This has been an exciting and fulfilling position enabling me to make a difference to the teaching timetable in dementia care and continue to work with carers and people with dementia. Last year I accepted the opportunity to study as a full-time student for a PhD.

#### About the Admiral Nurse Service:

The Admiral Nurse Service was established in the early 1990's, the name came from the family who instigated the set up the service and still actively support it. They cared for their father, Joseph Levy who had vascular dementia he loved sailing, his nickname was 'Admiral Joe' hence Admiral Nurses.

Admiral Nurses are specialist mental health nurses who work in the community with families, people with dementia and their social networks. There are currently 50 Admiral Nurses in England, and expansion of the service is a priority.

Admiral Nurses work with family carers and people with dementia:

- as the prime focus of their intervention;
- to provide practical advice, emotional support and information. They use psychosocial skills to educate and support the management of the care of a person with dementia;
- consult with service providers within appropriate timelines;
- Deliver education and training in dementia care and carer's needs;
- Make available consultancy to professionals working with people with dementia and their families; and
- Promote best practice in quality person-centred dementia care.

The individual Admiral Nurses work to a Competency Framework introduced in 2003 but putting this framework into practice has not appeared to resolve with the increasing demand for written evidence of how Admiral Nurses work effectively. In May 2005 *for dementia* commissioned a piece of qualitative research 'Carer's Experiences of the Admiral Nursing Service'. It was designed to evaluate carer's views on the achievement of three of the Admiral Nurse Service Standards. The document provides a rich source of appreciative data of the Admiral Nurse Service but suggests that an enhanced framework for the Admiral Nurse Service is possibly desirable to demonstrate in a constructive way how Admiral Nurses achieve the anecdotal high standard of care.

#### About the study:

The full title of my research study is:

**Family-centred Admiral Nursing: Re-conceptualising practice values.**

The research has been funded for three years; this includes the time to write up the study at the end (January 2009). The focus of the study is on the construction of an identity of family-centred care for Admiral Nursing. In addition to Admiral Nurses in England I will be actively asking people who are working as part of and associated with the Admiral Nursing Service to be part of the research study. Admiral Nurses, carers, people with dementia and other key stakeholders (managers and trustees) who have or have had an involvement with the service in England will be invited to participate.

The study is divided into three phases:

The design of the study examines the Admiral Nursing Service by asking about what is going well? Or what works well, or less well? Information or data gathered is then collected over the phases of the research study from all the participants and analysed by me. Each phase of the study will build on the knowledge and values of individuals and groups to see if a family-centred framework of working will be beneficial to the way the Admiral Nurse Service works.

The different phases of the study will introduce different ways of collecting the data. All participants will be asked to complete a consent form before they complete a questionnaire, join a focus group, or complete a telephone interview.

#### Phase 1

In phase one the Admiral Nurses will be invited to complete a questionnaire about their practice. The data from the questionnaires will be returned to me via *for dementia* to ensure the confidentiality of each Admiral Nurse and Admiral Nurse Service. This data will then be analysed by me and the information used with the supporting literature about family-centred care, to start discussions in phases two and three of the study.

#### Phase 2

In phase two of the study carers who are members of the United Carers Research Group *for dementia* will be invited to participate in focus groups ( 6-10 people) or telephone interviews to identify a 'competency framework' for carers. All the focus groups and telephone interviews will be audio taped and the information analysed. Photographs may be taken during the groups that may be used in future presentations or publications of the research study.

Participants who request not to be audio taped and/or photographed will be invited to participate in a telephone interview. This will mean developing the expertise of carers alongside phase three.

If you are interested in joining the United Carers Research Group please contact  
[joy.watkins@fordementia.org.uk](mailto:joy.watkins@fordementia.org.uk) or  
telephone 0207 874 7210.

#### Phase 3

In phase three, participants will be invited to attend focus groups or complete a one to one telephone interview. All the focus groups and telephone interviews will be audio taped and the information analysed. Photographs may be taken during the groups which may be used in future presentations or publications of the research study. Participants who request not to be audio taped and/or photographed will be invited to participate in a telephone interview.

All the data collected throughout the study will be anonymised, coded and stored in a locked environment on a removal memory stick according to the Data Protection Act 1998. The final written analysis will be available for you to see and material will remain confidential but can be removed from the analysis on your request. Photographs can also be removed from the study should you request it.

#### **Who is funding the study?**

*for dementia* are funding the three year research study and Northumbria University in Newcastle are sponsoring the study. I will still be working at Canterbury Christ Church University two days a week to carry on my teaching role in Dementia Care and consultancy work in the Dementia Service Development Centre South East.

To support the costs any telephone calls will be made by me and I will travel to the meet the focus groups. I do not have a budget to pay for the advice and expertise of participants but hope that you will be willing to join the study to share your valuable views on this subject.

**What if I join the study and want to leave?**

You may be invited to be part of all the phases or just one of them or you may prefer to take part in a phase that is most relevant to you. The study has been designed to allow participants to join and leave as they feel comfortable. You are free to join and leave the study without any explanation. This will not affect your contact with the Admiral Nurse Service in any way. I am happy to talk to you should you be feeling uneasy or have questions or you can contact Joy Watkins United Carers *for dementia* by emailing [joy.watkins@fordementia.org.uk](mailto:joy.watkins@fordementia.org.uk) telephone 0207 874 7210 or myself at [penny.hibberd@canterbury.ac.uk](mailto:penny.hibberd@canterbury.ac.uk) telephone 01227 782602.

Sometimes issues can be raised when participating in research that raises feelings or problems that require support and/or further information that is personal to you. If this arises and you would like to be supported please contact either myself Penny Hibberd [penny.hibberd@canterbury.ac.uk](mailto:penny.hibberd@canterbury.ac.uk) telephone 01227 782602 or Joy Watkins [joy.watkins@fordementia.org.uk](mailto:joy.watkins@fordementia.org.uk) telephone 0207 874 7210.

If you join the study and have cause for concern or complaint this should be directed to Barbara Stephens Chief Executive *for dementia* [barbara.stephens@fordementia.org.uk](mailto:barbara.stephens@fordementia.org.uk) telephone 0207 274 7210 where the information will be dealt with using the *for dementia* criteria for complaints.

**Many thanks for taking time to read this information if you would like any further advice about joining the study as a participant or would like to be kept up to date about the study please contact me by email [penny.hibberd@canterbury.ac.uk](mailto:penny.hibberd@canterbury.ac.uk) or telephone 01227 782602 there is an answer phone when the office is unattended.**

**Penny Hibberd RGN, RMN, DN, DipPP (Older People), MCGI, Bsc(Hons) Dementia Care, PGCLT(HE), Phd student.**

## Appendix 6 Carers invitation to participate



Penny Hibberd  
Admiral Nurse/Senior Lecturer  
PhD Student  
Canterbury Christ Church University  
Faculty of Health and Social Care  
Department of Social Care, Community & Mental Health  
North Holmes Road  
Canterbury  
Kent CT1 1QU  
Email: [penny.hibberd@canterbury.ac.uk](mailto:penny.hibberd@canterbury.ac.uk)  
Telephone: 01227 782606

October 2007

Dear

I understand from Joy at Uniting Carers *for dementia* that you are interested in participating in my research study called Family-centred Admiral Nursing: Re-conceptualising practice values. Please do not be put off by the name PhD studies often have very academic titles.

You may like to know a little about me before deciding. My name is Penny Hibberd I have been nursing since 1975 when I qualified in London as a general and mental health nurse. I have had a varied nursing career that I have continued with whilst my three daughters grew up. I have been an Admiral Nurse in Kent for the last 7 years combining Admiral Nursing with teaching dementia care at Canterbury Christ Church University for the last 4 years. My job as an Admiral Nurse and more recently as a Senior Lecturer has been interesting and fulfilling in fact one of the most enjoyable nursing jobs I have had. In January 2006 I accepted the opportunity to study for a PhD at Northumbria University in partnership with *for dementia*. My teaching role is continuing 2 days a week at the University.

The research study is about looking at how Admiral Nurses work now and then talking to a range of people working in and connected to the Admiral Nurse Service to see if Admiral Nurses could work with the families and the person with dementia. Another part of the research will be asking carers about what things they can or did well because they already had skills from their past experiences/lives and knowledge about the person they were caring for. The information I collect (data) will be analysed and then put together to form a framework for Admiral Nurses. This will help with the expansion of the service and explaining what Admiral Nurses do.

There is written information about the research study with this letter that Joy has sent you. The leaflet sets out all the phases of the study and you may have questions you would like to ask me or would like explained. There is also a sheet headed guidelines. This is an outline of you might expect to do or be included in. It is quite broad as in a research study the content can change as time goes on and the research develops but it will give you an idea of what you may like to participate in.

I would like to phone you to say 'hello', answer any queries and discuss what would be expected of you should you decide to help me in part of the study. If it is alright for me to phone you please can you let Joy know and she will pass your details to me. If at any point you would prefer not to be involved any more that is alright just let me or Joy know and we will make sure you do not receive any more material or until you are ready.

I am looking forward to this part of the research study as it is an opportunity for carers to contribute and is essential to its success and the future development of the Admiral Nurse Service.

Best Wishes,

Penny Hibberd

email: [penny.hibberd@canterbury.ac.uk](mailto:penny.hibberd@canterbury.ac.uk)

telephone: 01227 782602 (there is an answer phone when the office is unattended) Joy Watkins

email: [joy.watkins@fordementia.org.uk](mailto:joy.watkins@fordementia.org.uk) telephone: 0207 874 7210

## **Appendix 7 Telephone interview questions**



## **Questions for Telephone Interviews Research Study Group**

1. Tell me about a time you felt things went/have been going well? *This may have been a period of time for example, minutes, hours, days or months.*
  2. How did that make you feel? *For example contented, happy, relaxed.*
  3. Was there anything about the relationship with the people around you that made this go well? *For example a family member, a professional person, a friend, practical things like a stair lift or shopping being delivered.*

**Appendix 8 Transcript of telephone interview (A6)**

28<sup>th</sup> November Time 11.00am Duration 20mins Code: A6

<i>Diagnosis</i>	<p>you know that first of all Pick's leaves a lot mental acumen still there it certainly isn't like Alzheimer's or any of the other things and I found it much more difficult than other people seem to have caring for someone with dementia</p>
<i>Mobility</i>	<p>you are asking about perhaps when things went well – we just had little bits he refused to walk I used to take him he was able to walk. I used to take him for a 14 mile drive every day a round trip in the middle of it we went to the xx and he fed the ducks and that sort of pleased me that he was doing anything at all and after a little while he said no, no that's for children so we stopped doing it. He loved listening to music and that helped me gave me a sort of when I could wash and he listened to the same music over and over again and also one or two videos he used to watch constantly and that was sort of good for me the other thing that was a bit of a bonus he had as second stay in hospital he had 2 periods in hospital and the second one was actually oh when an Admiral Nurse said he can't stay here like that and he went into hospital again and he had very, very regimented behaviour before that he had to do everything was to the clock, meals had to be at certain times and always exactly the same and er lunch sort of had to be at 5 past 1 er and if I gave it to him earlier than that he looked at me as if there was something wrong with me.</p>
<i>Transport (driving)</i>	<p>He went into hospital for this period of time and they completely took away all that regimentation so I was very pleased that when he eventually did come out of hospital er reluctantly he seemed to find it like a security and we went backwards and forwards quite a lot like he used to come home on leave as they call it and he would ask me to take him back at sort of 5am in the morning I used to plead with him to stay</p>
<i>Enjoyable activities</i>	
<i>Relationship between pwd and carer</i>	
<i>Music</i>	
<i>DVD's</i>	
<i>Recognition of relationship changes</i>	
<i>Admission to hospital</i>	
<i>Support of AN</i>	
<i>Recognition of changes in relationship with pwd</i>	
<i>Routine</i>	
<i>Changing behaviour</i>	

<p><i>Relationships with pwd difficult</i></p> <p><i>eating and drinking</i></p>	<p>at home and he used to say no, no I must go and I would take him back to the hospital but eventually they said he must go home and after that he lost that regimented behaviour and also he would eat anything which made it much, much easier for me that was great relief.</p> <p><b>that must have been difficult keeping to such a rigid routine?</b></p>	
<p><i>Knowing the person (pwd)</i></p>	<p>well I just sought of accepted it perhaps it might have even been easier I knew exactly what I had to do all the time. I must tell you that we worked together my husband was a solicitor and we worked together for about 40 years so were used to being closeted together and he was always the leader and one of the things I found most difficult was the role reversal he was very noisy, extrovert and he became completely quiet introvert and I had to take over as leader. That was another thing that was very difficult.</p>	
<p><i>Accepting changes in relationship</i></p> <p><i>'Giving' all the time</i></p>	<p><b>so you mentioned having some time for yourself or snatches of it when he was listening to music or watching the video how did that make you feel being able to have that time for you?</b></p>	
<p><i>Managing risk</i></p>	<p>well I was always watching I always felt I was on 24 hour call I had to keep the front door locked in case he wandered off and I don't think I really I probably just felt a little less stressed. I found it impossible to relax it was very difficult 24 call very difficult nights um and I for a long time I didn't even sleep in a bed because it was easier to sort of get out of a reclining chair than to get in and out of bed.</p>	
<p><i>Sleep</i></p>	<p><b>So his periods in hospital what did that mean for you?</b></p>	
<p><i>Respite</i></p> <p><i>Knowing (he) was</i></p>	<p>Well it certainly gave <i>difficult to hear</i> I spent at least 5 hours a day at the hospital the whole of the visiting time it was in a mental health unit and um actually I felt happy that he was being looked after and</p>	

<i>being cared for Acceptance of changes in relationships</i>	also you get to know people they seem to have regular visits and I was sort of doing a ward round every day when I arrived because I had to ask everyone how they were and we did go out within the hospital grounds or I could take him for a drive but he always wanted to be back at the hospital. Once one of the doctors said to me why is he back here? and I said well it must be something about your personality that I don't have.	
<i>Feeling out of control with realtionship</i>	<b>Do you think he felt save there then?</b>  I think so he felt secure I don't know initially there was a lot of paranoid behaviour that he was umm being watched, there were people in rooms he wouldn't go passed one of the rooms because there were people there and I found that very frightening actually because er I didn't know quite how to cope with it we all come to it complete amateurs, completely uninitiated and that was difficult and eventually he became doubly incontinent and then I that was very, very stressful.	
<i>Symptoms of dementia Knowledge and experience</i>	<b>This was at home was it?</b>  He was at home I suppose about a year at home and eventually it was the Admiral Nurse and I was also attached to the Care Groups they all told me I wasn't coping because you know when you are in the middle of it you just go on day by day	
<i>Continence</i>	<b>When you are in a relationship it can be difficult to see that the relationship is changing</b>  well yes I felt that I was well it is a living bereavement um and I felt um that wasn't my husband and I was looking after someone and I was almost like a nurse and I really didn't know him and I often didn't like him	
<i>Support of AN Carer Groups</i>	<b>He had obviously changed a lot from the days when you worked together?</b>	
<i>Changing relationship Balancing the changing relationship</i>		

	<p>completely changed I would align it to children people with dementia it is constantly me, me, me and they are completely indifferent to everyone else</p> <p><b>Edith you were talking about the Admiral Nurses and x and how they talked to you about how you managing at home. Did you find that useful?</b></p> <p>I found it absolutely wonderful the Admiral Nurse who came to me initially just sort of turned up on my door step she was sent I think by the hospital and she absolutely saved my life I didn't know what to do or how to cope or how to manage and she was always available and she said if you want to scream at somebody just scream at me on the telephone. Then I did attend several care groups one of the groups was the group the Admiral Nurse ran in the x area and I still attend those groups and the other one was x and I did attend those groups constantly because I found the support was fantastic you can be completely uninhibited because everyone is in a similar situation and they are always sympathetic and they don't say is he getting better? and actually I don't know if you have heard but I do a carers group when they are training carers and one of the things they ask is was their anything positive and what came out of it was I developed lasting friendships and also it changed my personality because I was always very introvert I would never speak out but now not only can I speak in a room full of people but I can speak in front of perhaps 20 people who are in a training session to answer their questions which I could never have done before that is rewarding and satisfying <b>researcher validates this</b> well now that I feel I can help as well I feel it is an achievement because I would never have envisaged doing any of the things I do now I do telephone support I go to care groups I volunteer at care groups and actually help to run one so well it sounds a lot when I say it all together but it is not that busy but actually my life still revolves completely around dementia.</p>	
<i>AN availability Coping strategies, groups, sharing</i>		
<i>Support, empathy, information</i>		
<i>New friends and relationships</i>		
<i>Giving back, achievement</i>		

	<b>Was there any one else when you were at home with P and you were caring at home or hospital?</b>  Friends disappeared as if we had the plague; P's sister visited him constantly and my own children I have 3 children they were very supportive of course they didn't .... none of them lived near err they did visit whenever they could and they were very very supportive and also I was very lucky that I had a lady who helped me in the house and she was always available if I wanted to go out er because I found although there was help via not x but a similar organisation P was so unwilling and so resistant to it I could never relax when I did take the opportunity and eventually this lady who was the domestic help stayed two or three nights a week so I could get some sleep that was wonderful she was able to sort of field him from me there was only once he ever got to me <b>that must have been a very special relationship between her and P?</b> because I had always been full time at work she had been with me for about 20 years and he accepted her ands he accepted him <b>so it had grown over the years?</b> yes with the whole family it was quite a large Irish family and they were 14 brothers and sisters I only knew the ladies they were always a tremendous group <b>did the others support you as well?</b> no she was the only one <b>she sounds like a wonderful lady?</b> oh yes she was tremendous because I remember when he first came out of hospital on the first occasion and I know now they call it disinhibition er and there were always things he was aware he shouldn't do um he probably knew I could hear things but when he thought I was out of ear shot he said to her 'are you going to take all your clothes off for me?' and she said 'no, no it's a bit cold today' nothing would have phased her no. That was one of the problems he was constantly stripping off in the hospital.	
<i>Family relationships &amp; support</i>		
<i>Practical help in the house</i>		
<i>Sleep</i>		
<i>Knowing the person with dementia</i>		
<i>Acceptance stabilising</i>		
	<b>Is there anything else?</b>	

	<p><i>Practical aids</i></p> <p>I think I have told you just about everything and I ended up with all this double incontinence I bought an electric carpet washer I got tired of scrubbing carpets in the middle of the night that was I think and I have found with other people as well that incontinence is often the last straw because it is so difficult to cope with and it was just impossible and you know I would find him completely smothered on the bed and the pads would be removed or helpfully stuffed down the toilet and I used to find I didn't know which bit of him to touch first. I think the incontinence is always very, very difficult because then he did spend 11 months in residential care and they were absolutely wonderful I can't speak highly enough of them and I still visit the nursing home.</p>	
	<p><i>Continence</i></p> <p><b>What were you feeling like in that period?</b></p> <p>errrr completely guilty yes I think everybody is exactly the same and also because P never went into the um happy state er I did a round trip every day which was about 15 miles round trip and I would arrive and he would say 'going home with you now?' and I would say well you are not quite better and he used to say 'well go, go now' and he threw me out every single day.</p>	
	<p><i>Rejection Guilt</i></p> <p><b>That must have been difficult?</b></p> <p>well I just accepted that they did have a little coffee bar and if I could persuade him to come down and have a cup of tea or coffee then I stayed a little longer <b>did he enjoy that?</b> yes I am still friendly with a lot of the staff even though he was only there for a relatively short time 11 months I am still friendly with them and they were absolutely dedicated <b>so you built up relationships there?</b> yes all the relationships I have now are because of this period. <b>so have you found yourself with new friendships</b></p>	

## **Appendix 9 Coding sample**

Family Centred Admiral Nursing  
Telephone Interviews  
Carers Research Study Group  
coding (Nvivo7)

### **Stabilising**

#### **Reference 1 - 2.45% Coverage**

at all and after a little while he said no, I used to take him for a 14 mile drive every day a round trip in the middle of it we went to the Serpentine and he fed the ducks and that sort of pleased me that he was doing any no that's for children so we stopped doing it.

#### **Reference 2 - 3.10% Coverage**

I must tell you that we worked together my husband was a solicitor and we worked together for about 40 years so were used to being closeted together and he was always the leader and one of the things I found most difficult was the role reversal he was very noisy, extrovert and he became completely quiet introvert and I had to take over as leader.

#### **Reference 3 - 3.64% Coverage**

Then I did attend several care groups one of the groups was the group the Admiral Nurse ran in the Brent area and I still attend those groups and the other one was Jewish Care and I did attend those groups constantly because I found the support was fantastic you can be completely uninhibited because everyone is in a similar situation and they are always sympathetic and they don't say is he getting better?

#### **Reference 4 - 4.39% Coverage**

I do a carers group when they are training carers and one of the things they ask is was their anything positive and what came out of it was I developed lasting friendships and also it changed my personality because I was always very introvert I would never speak out but now not only can I speak in a room full of people but I can speak in front of perhaps 20 people who are in a training session to answer their questions which I could never have done before that is rewarding and satisfying

#### **Reference 5 - 3.32% Coverage**

now that I feel I can help as well I feel it is an achievement because I would never have envisaged doing any of the things I do now I do telephone support I go to care groups I volunteer at care groups and actually help to run one so well it sounds a lot when I say it all together but it is not that busy but actually my life still revolves completely around dementia.  
**Reference 5 - 1.72% Coverage**

she went into care and I have always been able to talk to my mum about stuff like that but my dad seemed to really, I would, I can feel he has closed down it is almost like he has put a wall between himself and her illness, you know and he cannot get over the wall my dad seemed to

really, I would, I can feel he has closed down it is almost like he has put a wall between himself and her illness, you know and he cannot get over the wall to the other side.

#### Reference 7 - 3.90% Coverage

Yes my husband is brilliant he is absolutely brilliant and there are times when I get upset about what has happened to my mum she now is in the late stage dementia she sleeps a lot of the time she is unresponsive I know she doesn't always recognise us and that is quite hard and you know that it is coming you have seen all the stages you have worked through the stages but its still its very sad and I talk to my husband about it a lot and he is absolutely fantastic and he has been fantastic in supporting me in my relationship with my father umm so umm you know I have the support of him and my daughter which is lovely because even though she is only 12 now she makes more sense about my mothers illness than my father has ever tried to which is good because it means that I know that when I come home I have the support of both of them and one of the really nice things on Friday nights is to give up and sit down with everybody and relax and have a nice family time is one of the things I really like about the end of the week

#### Reference 8 - 2.54% Coverage

she is not in London anymore but she helped me tremendously with umm you know some of the, some of the things my mum had gone through, some of the changes that were taking place, what to expect, you know when some of those things happened. It was just really nice to have somebody else to talk to and other than that the experience at for dementia of sharing in workshops and talking to other people who have been through exactly the same thing as you or are just about to go through the same thing as you are talking about umm those experiences you know and exchanging views and helping other people is the other way umm that you umm you get to talk about what has happened

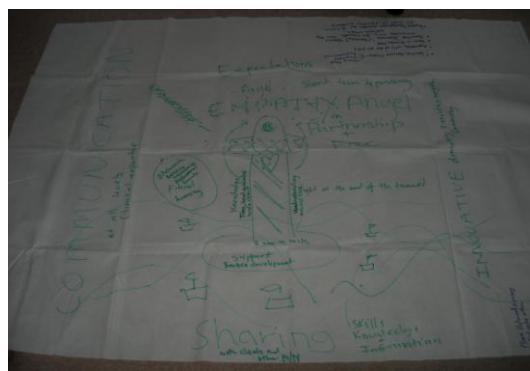
#### Reference 10 - 2.84% Coverage

part of err a large project that's taking place umm at the Hospital but that has also given me something, some, another way of, of another outlet to talk about what's been happening in a sense. It is not only what is happening for my mum it is what's happening to us as a family of carers and care givers umm so that's been positive as well and its been nice because they've been to see my mum at her home and umm I know she doesn't recognise the girls that come in anymore but they have built up a relationship with her over the 4 years and that's quite nice for me to see someone else can come in and have an interaction with her other than just family members because most of her friends are now as old as she is have just stopped coming to see her.

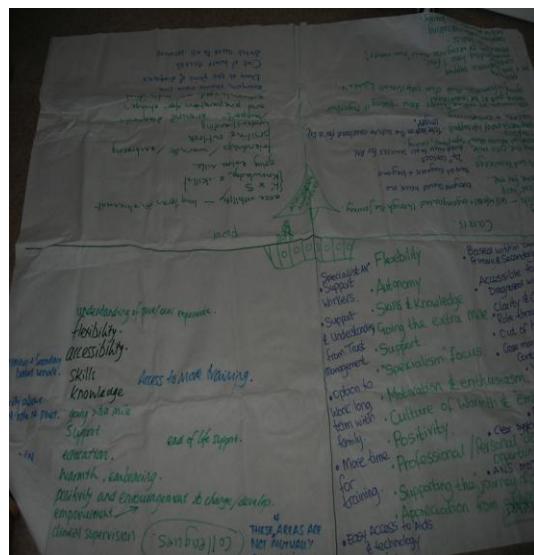
**Appendix 10 Example of mind map (person with dementia)**



**Appendix 11 Example of mind map (Admiral Nurses)**



**Appendix 12 Example of mind map (Admiral Nurses)**



## **Appendix 13 Guidelines for photography and narratives**



### **Family-centred Admiral Nursing**

Carer Research Study Group Part 2

#### **Guidelines for using your camera**

Your camera takes 27 pictures and has a flash facility so that you can take indoor pictures or in poor light. I will only need 6 pictures from you but you may like to take more so that you can choose the ones that you feel you would like to be part of the study, and if your photography is anything like mine ensures that the intended picture comes out.

You have given written consent to have your picture taken but no one else you know has. This is important to think about when taking your pictures. If you feel very strongly that a person should be in the picture please talk to them about it and show them the information about the study if they say yes you can go ahead. The picture cannot show their face, this is to protect their identity. Once you have the pictures back you will then have to go back to the person/people, show them the picture and obtain written consent on my behalf. I can give you the form and more information sheets just let me know how many. If something untoward happens to the camera let me know and I will replace it for you.

If any of the people you include have dementia they must be able to give written consent or their carer must be able to give a written statement to say that they would be happy to have their picture used.

This does sound very formal but it is very important to safeguard the privacy, dignity and choice of anyone who is included in the study.

In the pack I have sent you there is an envelope to return the camera to me. When I receive it I will code it and then get it developed. I will return the pictures to you as soon as I can. There will be two sets of pictures one set for you to keep and one for me. At this stage you can choose which pictures are used in the study. I will send some information about what to do with your chosen pictures in that package.

#### **Taking the pictures:**

After I spoke to you on the phone I went through all the conversations and picked out the main themes. I have placed them in the order of how many times they were raised in our conversations. Some you may recognise, it doesn't matter if you don't all your contributions are very important to the study.

The themes that came up as being most important are:

- information – giving, receiving, sharing. This was written and verbal information and was often about how it was given and who by.
- the Admiral Nurse or Admiral Nursing service – being there, support, relationship with you the person you are caring for and other organisations.
- family relationships – family members helping and being there, maintaining them, preserving a sense of normality.

- relationships for you as a carer – between you and the person you care/cared for, between other family members/ with friends and with professionals providing a service.
- relationships for the person you care/cared for – their relationship with you, their family, their friends, with professionals who provide/provided a service.
- spending time together – the things you do/did together, this theme was mainly about what you do or did on your own together.
- sharing – with the person you care/cared for, family, friends, professionals and services. Sometimes this was about emotions and sometimes about practical things.

**When you take your pictures I would like you to think about:**

**What were your feelings, skills or knowledge that makes/made that event/time important for you?**

Examples may be:

- You and the person you care/cared for had always enjoyed doing that e.g. walking in the park, listening to music. The picture might be off the park, the CD cover.
- Helping the person you care/cared for with daily living tasks e.g. washing, bathing, and dressing. The picture might be of the person's favourite perfume, a piece of clothing.
- Meeting up with friends and family e.g. having a meal together. The picture might be of the room or place where you meet/met.
- A particular professional or voluntary service that have helped you e.g. with information or support, respite, a place for the person you care for/cared for to live. The picture might be of a building, a leaflet about the service or something that reminds you of a particular person.

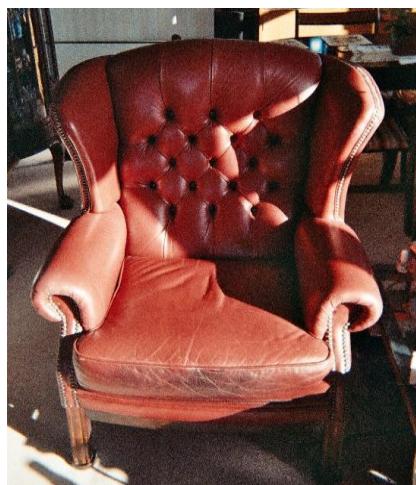
Lastly just to remind you that participation is voluntary and you do not have to participate if you would prefer not to. If you have any questions or would like to talk through any of the above please either email me or give me a ring.

Many thanks for all your time and commitment to the study.

Penny Hibberd PhD student  
 Telephone: 01227 782602  
 Email: [penny.hibberd@canterbury.ac.uk](mailto:penny.hibberd@canterbury.ac.uk)

## Appendix 14 Photographs and narratives

### Carer A1



A1 photograph and narrative 1/6

I like this photo of A's chair which was her favourite. I can often see her sitting there watching the television. It seems so real.



A1 photograph and narrative 2/6

Two views of the Turkish Tent from the Gothic Temple; a view of which A never tired.



A1 photograph and narrative 3/6

This photo was taken in front of the Turkish Tent at XX Park where A's ashes are scattered. A loved the park and at one time used to help as a volunteer. She was enchanted with the view over the lake.



A1 photograph and narrative 4/6  
This is another view of where her ashes  
are scattered



A1 photograph and narrative 5/6

Some relics from Ceylon (now Sri Lanka). As A was born in Ceylon and lived there until she was nine years old, she loved everything about the Island.



A1 6/6 Statues of Buddha. Having spent nine years of her childhood in Ceylon and having an ayah as her nanny, A had quite a strong affinity with Buddha.

## Carer A2



### A2 photograph and narrative 1/6

This is the house where we spent 50 years of married life. The open front door illustrates that people come and go.



### A2 photograph and narrative 2/6

This is the corner of a room with objects illustrating a wide range of activity. On the chair is the case he took to council meetings, he was a councillor for sixteen years. On the shelf behind are vinyl 33's include, Zorba the Greek, original sound track, My Favourite Greek Songs, Nana Mouskouri and Songs for Greek Lovers, Mikis Theodrakis. The portable mirror is that placed where he could watch TV whilst I shaved him.



### A2 photograph and narrative 3/6

We have two cats who were a part of our life. This is one in the kitchen, the centre of our home with its outlook on to the greenery. Our two cats were usually with us.



#### A2 photograph and narrative 4/6

The builder who with his team represent care and companionship over the last six years whilst making the house comfortable for our retirement. T the builder working outside our house so that the sawdust did not go all over the carpets. This is what builders do in this area because the Victorian houses have been divided into flats with little space for their equipment. We had a programme of refurbishment to make our house comfortable for retirement. The builder's team was very patient and became friends. We were both interested in their progress. They started in 2001 and had not finished when C died in 2006.



#### A2 photograph and narrative 5/6

A Greek restaurant where many happy hours were spent eating with friends and family for celebrations.



#### A2 photograph and narrative 6/6

Alexandra Palace, another example of a community space where a studio on the ground floor underneath the tower was used by the Cypriot Elderly. Other events were observed from the balcony under the gabled part of the palace. C was on the committee of the Councillors who made decisions about the use of this building.

### Carer A3



A3 photograph and narrative 1/6

My dad spends a lot of time reading the paper. I am never sure how much ‘goes in’. But in the recent London Mayor race commented that he felt Boris was a ‘bit lightweight’.



A3 photograph and narrative 2/6

My dad has a lifelong interest in steam locomotives. He will always happily watch a DVD showing old footage of railways. His favourites are footage of the 1920’s and 1930’s presumably when his interest started. He liked other TV programmes especially snooker, and come dancing. Both visual spectacles not really requiring the story to be followed to closely. He enjoyed recent showings of Indiana Jones, commenting ‘its very boy’s own’.



A3 photograph and narrative 3/6

My dad enjoys going to the pub with me. It gives us a chance of one on one conversation often without interruption. It is perhaps the chance for our most meaningful interaction. Sometimes my daughter comes with us. Here she is giving him his change which usually produces surprise at the cost of beer. ‘A pint and an’ half £4.60p?



#### A3 photograph and narrative 4/6

My dad enjoys playing games with my daughter. He here plays ‘noughts and crosses’, where he is more successful, than pelmanism/pairs with her set of Disney princess cards, where his success tends to be from pure luck. He also sits with her as she plays computer games.



#### A3 photograph and narrative 5/6

My dad enjoys the visual. Here he is in a train museum, which puts him in the age he tends to have memories of. He also enjoys art exhibitions, though paintings that are of the impressionist school or earlier. He enjoyed the Camden Town School exhibition at the Tate. Forget modern art.



#### A3 photograph and narrative 6/6

My dad says he enjoys walking though he claims says he doesn’t walk so much these days. I think that what he likes best is being with family and me in particular. He also takes great joy in just watching my daughter grow up. He feels safe and memory can be ‘managed’ in a collective way. I can fill in the gaps when he forgets

## Carer A4



### A4 photograph and narrative 1/6

It is not just a window it is our window onto the outside world, now that we are flat bound. It is our source of light, and sunshine when the sun is out, for the window faces south. Through it, we see the world as it passes us by; we get to know a little bit about the people living opposite, without actually knowing them. For example, there is a family in the house directly facing us; when we moved here seven years ago; their two boys were young children. We have seen them grow into the teenagers they now are. The tree outside is very beautiful, especially when in leaf, and quite a number of birds come to rest in its shade in the summer. We also benefit from its shade during the hottest months. We feel connected to nature through this tree.



### A4 photograph and narrative 2/6

Plants are the only other living things sharing our space, and we both have always loved them. It illustrates growth and beauty. Caring for other forms of life makes us part of the bigger picture, so that we do not feel bogged down and limited by a narrow view of the world, and don't become too absorbed by our human difficulties.



### A4 photograph and narrative 3/6

The picture is not very good, as pictures go, but the CD represents music, the one other great love of ours. It illustrates a life-long passion for both of us. Music has been a BIG source of pleasure and comfort at all times. Memories of many moments spent with friends, sharing and enjoying music that appealed to us all. Memories of quiet listening. Present times too, when music is still a significant element in our daily fabric of life. It is the most accessible art form, as it transgresses most barriers and uses a universal language. Our lives would be intensely poorer without it. I cannot think of life without it. I know L would second my thoughts on what was a passion of his.

#### A4 photograph and narrative 4/6



This is a picture of tenderness and I like that. It represents the best and most immediate means of communication left to us: touch. The feelings of well-being come from the closeness we seem to achieve through holding/stroking hands. Whenever I have quiet moment I sit close to L and take his hand in my hand. It's a calm spiritual way of saying 'Hello' I am here for you and you for me.



#### A4 photograph and narrative 5/6

I chose this picture for the life energy it portrays in the shape of three of our young grandchildren clustering around L. It illustrates that despite the fracturing effect of Alzheimer's upon all of our lives we are still a family where affection and closeness matters. Seeing the grandchildren I see all that is good about life and the future of course. At the same time I am aware of how rooted they are in our lives and that those connections are healthy and strong.

#### A4 photograph and narrative 6/6



This picture reminds me of better days even though we were already struggling with dementia. It brings back memories of when each morning L (who was still walking at the time) greeted himself in the mirror with a 'hello', a big grin and a look of satisfaction as he left the bathroom on his way to the kitchen to have breakfast. His ritual was a sign of some sense of identity and or of self, a comforting when I thought of his dementia. It is good for me to think that this mirror gave him pleasure for some considerable time. It also brings a smile to my face every time I think about it, for L had been very vain pre-Alzheimer's, I used to tease him because of it. During those months post-diagnosis his own image enthralled him, and became for him a good tool of self recognition and self appreciation.

## Carer A5



A5 photograph and narrative 1/6

Record collection, mum likes classical music.



A5 photograph and narrative 2/6

Information collected from the day centre and posted (to me).



A5 photograph and narrative 3/6

Mobile scooter, mum is unable to walk far, (it) gets her about, she has been to Scotland, needs assistance with scooter.



A5 photograph and narrative 4/6

Art work this is with cut out fabrics.



A5 photograph and narrative 5/6

Hands, mum now has nails as she doesn't bite them anymore, now she has her nails painted. Mum like to wave her rings.



A5 photograph and narrative 6/6

Art work. Painting mum still enjoys drawing and colouring in picture

## Carer A6



### A6 photograph and narrative 1/6

This is one of the front of the Nursing Home, where P spent the last eleven months of his life. Everything about it was of tremendous comfort to me and the family. He was cared for so lovingly by a caring staff who were led by a dedicated Manager. When I visited daily, everyone was so warm and kind, as if we were wrapped in a 'comfort blanket'.

*This photo was removed to maintain the identity of staff and patients.*

### A6 photograph and narrative 2/6

This is of the coffee bar. P was always unwilling to allow me to stay for any period of time when I visited. However he would accompany me to the café where we could share tea and biscuits and socialise with the other residents and visitors. It was good to spend some time together.



### A6 photograph and narrative for 3/6 & 4/6

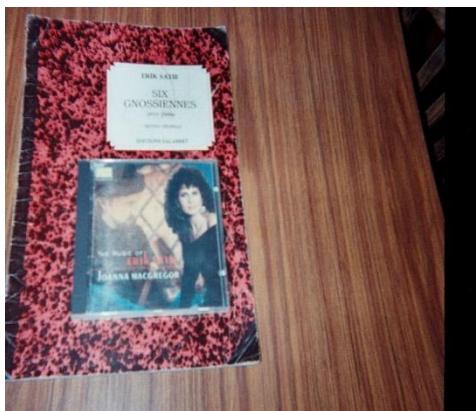
These are both pictures of the Rose Garden at the Inner Circle of Regents Park in London. We did a long drive each day through Hyde Park and Regents Park. Early on we would often stop at the Rose Garden and admire the lake and the flowers. Even perhaps stop and have lunch or tea. Eventually P refused to walk or even get out of the car and was always most anxious to go home.





#### A6 photograph and narrative 5/6

The Fish Finger. At one time in his illness, while still at home, P's diet became very restricted in content and equally at certain definite times. He would eat fish fingers at supper time and I was most grateful that there was always a supply available.



#### A6 photograph and narrative 6/6

P loved music and I always had some playing, even in the car. This collection by Eric Satie was a particular favourite and he always liked to hear it, especially when it was played by our younger daughter. It was the music we chose to be played at his funeral.

#### Carer A7

#### A7 photograph and narrative 1/6



I chose this photo of the home in which my mum now lives because it is her home. It took many months of searching for somewhere for my mum to live where I felt she would be happy and with people I thought would look after her needs. Once my mum was settled it removed that constant level of stress I was feeling and allowed me to pick up life with my own family after an incredibly difficult year. It was definitely the right choice for my mum and still is and the staff have managed the changing nature of her dementia with humour and all of the residents are treated with respect. I always know that when I leave my mum she will be well looked after in every respect and that has brought me the most peace of mind.

#### A7 photograph and narrative 2/6



I chose this photo of the garden at my mum's home because it represents several things to me. As you can see, it is a haven of peace and tranquility and on the many sunny days we have enjoyed in it the only thing you can hear is the sound of the birds and the children playing in the school fields that back onto it. We have used the summer house for birthday celebrations or to retire to when the heavens inevitably open during the unpredictable summer months. At certain times it is also a haven of fun and laughter because that is where the home holds its annual summer garden party. This is to raise money for the amenities funds which enables the residents to have days out at the seaside or frequent visits to the theatre. As a way of making it easier for my daughter to visit her grandmother, we ran a cake stall the first summer my mum was there and have continued to do so with each passing summer. For me it is the place I am able to relax most when I am visiting my mum and I enjoy the walks we take up and down the garden path looking at all the flowers.

#### A7 photograph and narrative 3/6



I chose this photo because it is the companion painting to the one in the previous photo. Both the paintings my mum produced at that time now hang in her room and although she can no longer remember they are her handiwork I do and it makes me happy to see them each time I visit her.

#### A7 photograph and narrative 4/6



I chose this photo because it is a picture my mum painted in the art therapy group at her home at the end of her first year there. The home organised for all the paintings to be framed and put on display in the dining room and a photographer from the local paper came and took photos of the mini exhibition. A photo of my daughter and my mum holding her painting was printed in the local newspaper and made everybody very proud. I think it helped us all to see that even though my mum was not well she was still able to try new things and to participate in group activities. As her illness has progressed and she is no longer able to take part in such activities, it has made me realise how important it is for people with dementia to be stimulated and to enjoy new hobbies whilst they are still able.

#### A7 photograph and narrative 5/6



I chose this first photo because it has a bottle of my mum's favourite perfumed talc in it. Having taken Power of Attorney over my mum's affairs in 2002, every drawer or wardrobe I have opened or any envelope of papers has the lingering smell of this scent. It will be one of the things I always remember about my mum and on the days I really miss her I open up the papers I have at home and the scent is a strong reminder of her presence. The other items in the photo - the dried flower arrangement from a neighbour and the ornaments which are presents from us - decorate her room and make her happy, which in turn makes me happy.

## A7 photograph and narrative 6/6



I chose this first photo because it is my mum's favourite chair in her room at the residential home in which she has lived since January 2003. It is the chair she sits in when we visit and also where she has chiropody and leg massage, which she really enjoys. We added a couple of cushions to make it more homely and my dad bought her the teddy bear at one of the social events at the home. As her dementia has progressed, it has become the spot she sleeps a lot too but I know that she is comfortable and often she will sit and read there. It makes me feel contented because I know that my mum has a space of her own to come back to but also that nurturing treatments take place when she is sitting there.

### Carer A8

All the photos participant A8 wished to use included pictures of her husband or family members. For that reason they do not appear here but are duly acknowledged as an important contribution to the thesis.

#### A8 1/6

This reminds me when he was around. He liked to sit in his favourite chair, read his books and newspapers and watch television.

#### A8 2/6

Because he was surrounded by the family and was happy when he came home. He is happy and smiling. He looks comfortable and relaxed at home.

#### A8 3/6

He came home for his first visit for his granddaughter's 3<sup>rd</sup> birthday party. We were celebrating a family occasion. The whole family were together.

#### A8 4/6

This is where he has been living since June 2007. It illustrates sadness at not being with his family. He is in his room eating his dinner. He is in safe surroundings and being taken care of but I have feelings of sadness.

#### A8 5/6

He always liked standing outside the front door of his house where he lived for many years. It illustrates how he used to socialise daily with his neighbours and friends, and to get fresh air. He liked to walk and would go out for many hours. He enjoyed going to the library. This picture shows him outdoors which he enjoyed, because at the nursing centre he spends most of his time indoors.

#### A8 6/6

This picture shows him spending most of his time in the lounge watching television, and listening to music. Sometimes he gets up and starts dancing with the nursing staff. He likes sitting in this particular chair which now appears to be his favourite chair. He is relaxed sitting in this chair, eating and watching television. This is similar to home, when he used to sit in his favourite chair to watch television.

## **Carer A9**

*This photo has not been included to maintain confidentiality of the participants of the picture.*

### A9 photograph and narrative 1/6

I chose this because it is of me and M. M came as a sitter for mum before she went to the home. She came from the BME group. She has kept up the relationship with my mum and has stayed involved through hospital admissions to now. Her involvement is voluntary and her relationship with mum and the family is very special to us all.

*This picture has been edited to exclude identifying pictures of family and staff*



*This picture has been edited to exclude identifying pictures of family and staff*

### A9 photograph and narrative 2/6

This is a picture of the manager of the home. Mum was the first person to go to live there. She was the only resident for a week. S\*\*\* has formed a special relationship with mum she is from Trinidad as well and understands mum. Mum now says what she thinks, this often seems blunt and to the point but S\*\* takes this in her stride.



### A9 photograph and narrative 3/6

This is a picture of my mum the lady behind her doesn't say much but when she does say something it is very apt. She has a great sense of humour. Mum asked 'have they fed her yet?' Mum insisted on reading all her cards, I feel grateful that she survived the heart attack and has been able to celebrate her 89<sup>th</sup> Birthday.

*This picture has been edited to exclude identifying pictures of family and staff*



#### A9 photograph and narrative 4/6

This is a picture of S, M and I. Mum was busy reading she just looked up as my son said her name and took the photo. The flowers, cake and things to eat are all significant in this picture. We are all significant in mum's life and I would have liked my son to have been in the picture too. Mum is in the centre with all of us around her.

*This photo has not been included to maintain confidentiality of the participants of the picture.*

#### A9 photograph and narrative 5/6

This is a picture of all the staff and us around mum. These are the people that have been with her from day one at the home. It is a great relief that mum is somewhere safe. I feel I have handed this weight over to S. Mum is well looked after and it was nice having them all there for her birthday.

*This photo has not been included to maintain confidentiality of the participants of the picture.*

#### A9 photograph and narrative 6/6

This is a happy photo. Mum has a lovely sense of humour. The carer in the middle has a special relationship with mum she kisses her and she polished mum's nails for her for the first time in her life. Mum is fascinated by her painted nails, she likes the attention and the closeness. Seeing mum happy and contented is like a load being taken off me.

## **Articles, presentations and posters arising from this thesis**

Hibberd, P., Keady, J., Lemmer, B., Reed, J., (2008) A family-centred approach to dementia care. *Journal of Dementia Care*, vol. 16, no. 5 26-27.

Hibberd, P., Keady, J., Lemmer, B., Reed, J., (2009) Using photographs and narratives to contextualize and map the experience of caring for a person with dementia. *Journal of Nursing and Healthcare of Chronic Illness* accepted for publication 31/05/09.

Poster presented at Northumbria University Post Graduate Research Conference July 2009  
What is the meaning of family-centred Admiral Nursing to Carers?

Conference presentation Admiral Nurse National Forum June 2010 What is the meaning of family-centred Admiral Nursing to Carers? A Research Journey.

Hibberd, P., (2010) What is the meaning of family-centred Admiral Nursing to Carers? AI Research notes Edited by Lena Holmberg and Jan Reed. *AI Practitioner* Volume 12 Number 3 ISBN 978-1-907549-02-156.

International Psychogeriatric Association International Conference 2010 poster presentation:  
'Typologies of caring relationships: using photographs and supportive narrative to contextualise and map the experience of caring at home for a person with dementia'.

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