



An evaluation of the end of life care experiences of people with dementia and their carers

Final Report | March 2015

Simon C Evans, Association for Dementia Studies

Karen Harrison-Dening, Dementia UK

Kate Read, Association for Dementia Studies

Acknowledgements

Firstly we would like to give huge thanks to the Admiral Nurses who gave substantial amounts of their time and experience to make this study happen.

We also thank the four families who took part in the study, without whom it could not have gone ahead.

Finally, thanks go to Professor Dawn Brooker and Kay de Vries (now with Victoria University of Wellington) for their contribution to the development of the study.

Table of Contents

Executive summary	4
Introduction and background	9
Admiral Nursing	9
Dementia and multimorbidity	10
Dementia: A life limiting condition	11
Policy developments in advance care planning.....	12
Study Aim and Objectives	14
Study Design and Methods	14
The Findings	18
Discussion.....	26
Conclusion.....	33
References.....	36
Appendix 1: The Mental Capacity Act (2005)	42
Appendix 2: Protocols to safe guard the person with dementia and the carer	43
Appendix 3: The Research Measures.....	44

Executive summary

Background

Admiral Nursing was first piloted in 1991 and by the end of 2013 there were 125 Admiral Nurses in England. Admiral Nurses are the only group of qualified nurses in the UK who focus on working with families affected by dementia. They are principally mental health nurses who, alongside other health and social care professionals, work with families, both the person with the diagnosis and their family carers, in order to help them to live positively, develop and maintain skills for coping and communication, and maintain relationships.

Life expectancy is increasing at a faster rate than healthy life expectancy; as a result people often develop a range of conditions and disabilities in the years of old age before death. The greatest users of the health and social care system are frail older people with multiple conditions, and age is strongly associated with cognitive impairment. Despite the impact that dementia and frailty have on older people and their families, they have not traditionally been conceptualised as 'terminal' or 'life limiting' syndromes. Dementia is a progressive, irreversible neurodegenerative condition and once it is diagnosed people will die with dementia regardless of the primary cause of death. Although dementia has been identified as one of the leading causes of death, exact numbers of deaths where dementia is a primary or secondary cause remain uncertain. This is thought to be due to under-reporting of dementia on death certificates.

People with dementia and cognitive impairment show high levels of multimorbidity, with common conditions including cardiovascular disease, diabetes, and musculoskeletal disorders such as fractures. Multimorbidity is characterised by complex interactions of co-existing diseases where a medical approach focused on a single disease does not suffice. People with dementia are more likely to experience under assessment and under treatment of any multimorbid condition than people with other long term conditions. Families affected by dementia often present their concerns and problems to the ANs in respect of other multimorbid illnesses, such as diabetes or cancer. These illnesses and conditions are in addition to the dementia and often present the carer with, for example, practical problems in following treatment regimes or in understanding prognosis. It is often when a multimorbid condition threatens the life of the person with dementia that

carers find decision making especially difficult and such events can expose how they may not fully understand the life limiting nature of dementia. As Admiral Nurse numbers increase and their scope of involvement often including the end of life of the person with dementia we need to have a greater understanding of the range of knowledge and skills required of them in ensuring they are better able to support families in the later stages of the illness.

Whilst many people with dementia die of a medical complication, such as pneumonia or another infection, dementia itself can be the cause death; for example, general wasting, malnutrition, and dehydration are real risks when a person with dementia can no longer eat safely and move independently. However, the stigma of the disease and the lack of recognition that dementia is a life limiting illness have led to neglect in addressing the end of life challenges for PWD and their carers.

The End of Life Care Strategy and the National Dementia Strategy both have significant potential for improving palliative and end of life care for PWD. The National Dementia Strategy details a five year plan to radically transform the quality of care for PWD and their carers'. The strategy, updated in 2015, has three key themes:

To improve awareness of dementia, among both the public and professionals.

To promote early and accurate diagnosis and intervention.

To deliver high quality care and support for people with dementia and their carers

These themes are addressed through 17 objectives. Particularly pertinent to this study is the twelfth objective: Improved end of life care for people with dementia.

“People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia”.

Within its stated 'case for change', the dementia strategy strongly emphasises the need to link any service development in end of life care for PWD to the Department's End of Life Strategy.

Aims and Methods

This report describes a project that aimed to explore the question of whether the Admiral Nursing supportive model of specialist care input can successfully provide care for people with dementia and their families at the end of life. Additional objectives included to increase understanding of the needs of people and their family carers in the last year of life, to explore the experiences of Admiral Nurses working with this group and to assess the suitability of a range of quantitative measures in this setting. Finally, it was hoped that the findings could inform the development of Admiral Nursing services and practice in providing end of life care. The study was commissioned by Dementia UK and carried out by the Association for Dementia Studies at the University of Worcester.

The research adopted a mixed methods approach to evaluating a prospective, longitudinal, community-based cohort pilot study that was carried out in the West Midlands over an 18 month period. A purposive sample of 4 patient/carer dyads were recruited by one Admiral Nurse from her existing and prospective client list. The main inclusion criteria were that they had at least one general predictor of end stage illness and the first four primary dementia specific indicators and any one of the secondary dementia indicators for advanced disease, as listed in The Gold Standard Framework Prognostic Indicator Guidance. An additional criterion was that the Admiral Nurse judged that the patient might die within the next 6-12 months.

Data were collected through detailed reflective diaries kept by the Admiral Nurse in relation to each dyad over a period of 12 months. In addition, the following quantitative measures were used: The Functional Assessment Staging (FAST) Scale; The Palliative Care Outcome Scale (POS); The Neuropsychiatric Questionnaire (NPI-Q); The COPE Index; The Carer's Assessment of Difficulties Index (CADI); and the Satisfaction with Care at the End-of-Life in Dementia (SWC-EOLD). Approval for the study was gained from an NHS Research Ethics Committee.

Findings

Experiences of using the standardised measures were mixed. Use of the Neuropsychiatric Questionnaire (NPI-Q), COPE Index and Carers Assessment of Difficulties Index (CADI)

appears to be relatively successfully across the four dyads. Implementation of the Palliative Care Outcome Scale (POS) was less successful, and the Satisfaction with End of Life Care in Dementia (SC-EOLD) tool was only appropriate for use with one dyad. However, closer inspection of the data has revealed a more complicated picture in terms of the amount of data that could be collected using each tool. For example, many of the questions included in the NPI-Q were felt by the Admiral Nurse to be inappropriate to ask or did not elicit a clear answer, leading to a high level of missing data. In contrast, although the Palliative Care Outcome Scale (POS) was only appropriate for use with two of the four dyads, where it was used it was fully completed.

The reflective diaries provide valuable insights into the experiences of spouses of people living with dementia at this stage in their illness. The sometimes overwhelming nature of this role is all too apparent, including its impact on opportunities for social interaction and on relationships with the wider family.

Our findings also provide insight into some of the effects that the Admiral Nursing role can have on those who perform it. The mixed emotions that can be triggered by this work are very apparent, as is the strong sense of responsibility felt when trying to provide the best possible care and support for families during a particularly difficult period.

Conclusion

This small in depth study provides unique insights into the role of Admiral Nurses who provide care and support towards the end of life. Within this context the findings provide valuable information about the potential impacts of Admiral Nursing on family carers and on the Nurses themselves, as well as describing the practical experiences of using a range of standardised measures.

Overall, the findings bear witness to the highly skilled and sensitive nature of Admiral Nursing, with its focus on facilitating exploration of carer's worst fears and best hopes. This role plays a hugely valuable part in planning for the end of the person's life and putting in place strategies to support aspirations. In this respect the Admiral Nursing service aligns closely with national and international policy for dementia, multimorbidity and end of life care.

The findings highlight some of the skills that lie at the heart of Admiral Nursing, which include advanced communication skills, reflective practice and emotional self-awareness. Comprehensive training in these areas and effective clinical supervision are essential to underpinning effective and sustainable practice.

There are some concerns that the use of standardised measures in this context can be a barrier to relationship building and may constrain therapeutic engagement. However, at the same time there is evidence that some of the tools used within the context of a therapeutic relationship may be helpful in drawing out issues which might otherwise be overlooked by the carer or professional supporting them. It would be helpful to have available a specific assessment tool for a person with dementia that encompasses both the behavioural and psychological impact and also the physical health aspects in the last months of their life. A tool which incorporates the NPI, wellbeing and physical symptoms would offer a more holistic approach. In addition, we suggest that there is a need for a tool which supports consideration of the future, both for the person with dementia at the end stages of their life and also for the ongoing life of the carer.

Limitations

This was a small scale study, based on relatively small amounts of data and the practice of a single Admiral Nurse, which has implications for the conclusions that can be drawn. However, the quality of the data that was collected, particularly in the form of some very insightful reflective diaries, leads us to believe that the study retains considerable value as an in depth exploration of the role of Admiral Nursing towards the end of life.

Introduction and background

Admiral Nursing

Admiral Nursing (AN) was first piloted in 1991 as a result of one family's negative experiences of caring for their father who had vascular dementia. Admiral Nurses (ANs) are the only group of qualified nurses in the UK who focus on working with families affected by dementia. They are principally mental health nurses who, alongside other health and social care professionals, work with families, both the person with the diagnosis and their family carers, in order to help them to live positively, develop and maintain skills for coping and communication, and maintain relationships (Bunn et al., 2013; Harrison Denning, 2010). As of the end of 2013, there were just over 125 Admiral Nurses in England, located in the following areas: London, Kent, Hertfordshire, Southampton, Yorkshire, the West Midlands, the North West and North East of England. Admiral Nurses are hosted and funded in NHS and social care trusts, not for profit organisations and care homes. Funding for such posts varies dependent upon the employing organisation. The charity Dementia UK provides a central organisational structure to support their work (www.dementiauk.org).

The evidence base for Admiral Nursing is limited. One quasi-experimental study was undertaken over ten years ago when Admiral Nursing was still in its developmental stages (Woods, 2003). This was a design using the General Health Questionnaire (GHQ) as an outcome measure for 104 family members in receipt of admiral nursing (n = 43) compared with regular CMHT involvement (n = 61). Over an 8 month period better outcomes were seen for anxiety and insomnia in the AN intervention group over usual care (P=0.038). The authors acknowledged a number of limitations to this study, including methodological challenges arising from differences in the population seeking AN intervention, such as randomisation and the need for a longer follow up period (Woods, 2003).

Only two other peer reviewed studies have been published about the role of AN. One of these used semi-structured interviews in 16 case studies to explore the decision making processes ANs engage in (Burton, 2005). The study demonstrated a high complexity of cases, with the decision to offer a service to carers influenced not only by perceived need, but also upon the nurses feeling professionally responsible for perceived gaps in service

provision. The second is a series of qualitative case studies that illustrate the practice of the AN (Keady et al., 2007). The remaining literature concerning ANs has been published in non peer-reviewed professional journals.

The focus of the study that forms the basis of this report, however, is not the role of the AN per se but the emerging need to support PWD and their families in care that is delivered towards the end of life. Before starting this research study, Dementia UK and Admiral Nurses had become increasingly interested in the role and function of ANs in palliative and end of life care in dementia (Harrison Denning, 2010).

Dementia and multimorbidity

As dementia is largely a disease of old age, many PWD will also have other co-morbid illnesses or disabilities. In medicine, co-morbidity is defined as one or more coexisting medical conditions or disease processes that are additional to an initial diagnosis.

Multimorbidity is defined as the co-existence of two or more chronic conditions, where one is not necessarily more central than the others (van den Akker et al., 1996; Boyd and Fortin, 2010). Multimorbidity correlates with age and represents the most common 'disease pattern' found among the elderly. Multimorbidity is characterised by complex interactions of co-existing diseases where a medical approach focused on a single disease does not suffice. People with dementia and cognitive impairment show high levels of multimorbidity (Cigolle et al., 2007; Doraiswamy et al., 2002), common conditions including cardiovascular disease, diabetes, and musculoskeletal disorders such as fractures.

Many studies have investigated the relationship between multimorbid conditions and dementia: prevalence and incidence; numbers of concurrent multimorbid conditions; and specific multimorbidities common in dementia such as under nutrition and weight loss, urinary tract infections and incontinence, pain, heart disease, etc. (Ahluwalia et al., 2011; Cigolle et al., 2007; Cronin-Stubbs et al., 1997; Doraiswamy et al., 2002; Eriksson et al., 2009; Feldt et al., 1998; Prince et al., 2011; Tschanz et al., 2004; Zuliani et al., 2011).

Tschanz et al. (2004) found that multimorbid medical conditions were positive predictors of mortality in dementia, although dementia itself was the strongest predictor of mortality, with the risk being two to three times greater than those of other life-shortening illnesses. However, through the pressure for diagnosis in policy and the Prime Ministers Challenge,

dementia has become the index condition which thus diagnostically overshadows all other conditions experienced by the individual (Iliffe 2013).

Multiple multimorbid conditions not only have a cumulative effect but also interact to have a multiplicative impact. Marengoni et al. (2011), in a systematic review of 41 papers, found the major consequences of multimorbidity were disability and functional decline, poor quality of life, and high health care costs. René et al. (2013) conducted a population-based cohort study, following 310 PWD longitudinally. They compared their trajectories with those of 679 people without dementia and found that multimorbidity was related to accelerated decline in PWD but not in non-demented individuals.

Moreover, PWD are more likely to experience under assessment and under treatment of any multimorbid condition than people with other long term conditions (Davies and Higginson, 2004). Families affected by dementia often present their concerns and problems to the ANs in respect of other multimorbid illnesses, such as diabetes or cancer. These illnesses and conditions are in addition to the dementia and often present the carer with, for example, practical problems in following treatment regimes or in understanding prognosis. It is often when a multimorbid condition threatens the life of the person with dementia that carers find decision making especially difficult and such events can expose how they may not fully understand the life limiting nature of dementia. As Admiral Nurse numbers increase and their scope of involvement often including the end of life of the person with dementia we need to have a greater understanding of the range of knowledge and skills required of them in ensuring they are better able to support families in the later stages of the illness.

Dementia: A life limiting condition

Life expectancy is increasing at a faster rate than healthy life expectancy (Froggatt, 2006); as a result people often develop a range of conditions and disabilities in the years of old age before death. The greatest users of the health and social care system are frail older people with multiple conditions, and age is strongly associated with cognitive impairment (Kulmala, 2014). Despite the impact that dementia and frailty have on older people and their families, they have not traditionally been conceptualised as ‘terminal’ or ‘life limiting’

syndromes (Sampson and Harrison Dening, 2013). In one study of nursing home carers and physicians, at nursing home admission only 1.1% of residents were perceived to have life expectancy of less than 6 months, while in fact 71% died within that period (Mitchell et al., 2004). Acute physical illness requiring emergency hospital admission, such as pneumonia or urinary tract infection, may be an indicator of imminent death in people with advanced dementia (Mitchell et al., 2009; Morrison and Siu, 2000; Sampson et al., 2009).

Dementia is a progressive, irreversible neurodegenerative condition (Neale et al., 2001; Wilcock et al., 2008; Xie et al., 2008) and once it is diagnosed people will die with dementia regardless of the primary cause of death (Wilcock et al., 2008). Although dementia has been identified as one of the leading causes of death (Foley and Carver, 2001), exact numbers of deaths where dementia is a primary or secondary cause remain uncertain (Harris et al., 2010). This is thought to be due to under-reporting of dementia on death certificates (Morgan and Clarke, 1995; Martyn and Pippard, 1998). However, Xie et al. (2008), from analysis of a longitudinal population based cohort study, reported that median survival time from symptom onset of dementia to death was 4.5 years and concluded that one in three people (30%) will die with or from dementia. Similarly, Rait et al. (2010) found that the median survival time from the diagnosis of dementia was 3.5 years. Despite UK estimates that approximately 100,000 people with dementia die each year (Bayer, 2006), Martyn & Pippard (1998) reported that fewer than 25% of people diagnosed with dementia during their life had their diagnosis recorded as an underlying cause of death on the death certificate.

Whilst many people with dementia die of a medical complication, such as pneumonia or another infection, dementia itself can be the cause of death; for example, general wasting, malnutrition, and dehydration are real risks when a person with dementia can no longer eat safely and move independently. However, the stigma of the disease and the lack of recognition that dementia is a life limiting illness have led to neglect in addressing the end of life challenges for PWD and their carers (Sampson et al., 2006).

Policy developments in advance care planning

The End of Life Care Strategy (DH, 2008) and the National Dementia Strategy (DH, 2009) both have significant potential for improving palliative and end of life care for PWD. The National Dementia Strategy (DH, 2009) details a five year plan to radically transform the

quality of care for PWD and their carers'. The strategy, updated in 2015, has three key themes:

- *To improve awareness of dementia, among both the public and professionals.*
- *To promote early and accurate diagnosis and intervention.*
- *To deliver high quality care and support for people with dementia and their carers*

These themes are addressed through 17 objectives. Particularly pertinent to this study is the twelfth objective:

Objective 12: Improved end of life care for people with dementia.

"People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia".

Within its stated 'case for change', the dementia strategy strongly emphasises the need to link any service development in end of life care for PWD to the Department's End of Life Strategy (DH, 2008).

Dementia is clearly a high priority not just within the UK but all other major countries, as evidenced by the recent G8 summit focusing on a global call to action on dementia (G8, 2013). No specific mention was made to end of life care for people with dementia, but there was an ambition to build upon research collaborations across the member countries to strengthen efforts to better meet the challenges that dementia presents society.

Recently, van der Steen et al. (2013) used a Delphi consensus process involving 64 experts from 23 European countries, including the UK, to provide the first definition of palliative care in dementia. This White paper presents a significant milestone to support the development of high quality palliative and end of life care in dementia. This is an area of great interest to Admiral nursing: translating this policy and guidance into nursing and multidisciplinary practice to support people affected by dementia and their families access high quality care throughout the trajectory of the illness but also at the end of life.

Study Aim and Objectives

This report describes a project that aimed to explore the question of whether the Admiral Nursing supportive model of specialist care input can successfully provide care for people with dementia and their families at the end of life. Additional objectives included to increase understanding of the needs of people and their family carers in the last year of life, to explore the experiences of Admiral Nurses working with this group and to assess the suitability of a range of quantitative measures in this setting. Finally, it was hoped that the findings could inform the development of Admiral Nursing services and practice in providing end of life care. The study was commissioned by Dementia UK and carried out by the Association for Dementia Studies at the University of Worcester.

Study Design and Methods

The research adopted a mixed methods approach to evaluating a prospective, longitudinal, community-based cohort pilot study that was carried out in the West Midlands over an 18 month period. The aim was for a purposive sample of a up to 16 patient/carer dyads in total, to be recruited by two Admiral Nurses from their existing and prospective client lists.

People with dementia on the Admiral Nurses case load or referred to the Admiral Nurse service over the first 6 months of the project were recruited to the study. The main inclusion criteria were that they had at least one general predictor of end stage illness and the first four primary dementia specific indicators and any one of the secondary dementia indicators for advanced disease, as listed in The Gold Standard Framework Prognostic Indicator Guidance (GSF, 2006). An additional criterion was that the Admiral Nurse judged that the patient might die within the next 6-12months. The GSF was developed in consultation with specialist clinical bodies, interest groups, palliative care textbooks and various prognostic indicators commonly used in the USA to enable health professionals to better identify adult patients with advanced disease nearing the end of their lives

People with dementia who did not meet the GSF prognostic indicator guidance for advanced/end stage disease on caseloads or at referral were not recruited to the study but were given the usual level of care and support by the Admiral Nurse.

Consent/assent

Competency to give valid consent was assessed using guidelines as defined by The Mental Capacity Act 2005 (Department of Constitutional Affairs, 2005). Family carers and people with dementia who had capacity to consent were given written and verbal information regarding the study and time if needed to discuss with the researcher their participation in the research. Where the person with dementia was unable to give fully informed consent, assent was sought from their next of kin, carer or someone close to the person (who does not receive remuneration for this role) who has Lasting Power of Attorney (LPA). Failing this, the main carer acted as a 'personal consultee'.

While it was perceived that the risk of harm to the person with dementia and or carer participating in this study was negligible, a protocol was developed in order to safeguard the individual with dementia and/or carer should this occur. Ethical approval for the study was gained from the North Wales Research Ethics Committee (Central and East) Ref. 11/WA/0330

Data Collection

Data were collected through detailed reflective diaries kept by the Admiral Nurses in relation to each dyad over a period of 12 months. The format used was based on the Gibbs model of reflection and significant events (Gibbs, 1998).

In addition, the following quantitative measures were used:

The Functional Assessment Staging (FAST) Scale, a tool developed and used both in research and clinical practice to chart the decline of people with Alzheimer's disease (Reisburg, 1988). In the present study the FAST Scale was used to assess severity of dementia, with a stage of 7 indicating a patient with severe advanced disease.

The Palliative Care Outcome Scale (POS), an assessment and measurement tool designed to meet the needs for simple and appropriate assessment. It is a short, easy-to-use questionnaire designed to assess clinical practice, with regards to patients' palliative care needs and palliative care outcomes (Aspinal *et al.*, 2002). The POS is used in routine clinical practice and covers patients' physical, psychological and practical needs and takes approximately five minutes to complete. The POS was used in this study to assess prevalence and severity of patients' symptoms using the 'Staff Questionnaire' which was administered to the carer. This asks the carer to reflect over the past 3 days if they have observed how the person with dementia has been feeling, what symptoms they have been experiencing and to rate the symptom on how they feel it affects the person with dementia.

The Neuropsychiatric Questionnaire (NPI-Q), a brief caregiver self-administered questionnaire that is used to assess non-cognitive symptoms commonly observed in people with dementia i.e. psychosis, mood disturbances, agitation, aggression, personality changes, pacing, wandering, disinhibition, changed sleep pattern and appetite disturbances (Kaufer *et al.*, 2000). Cummings *et al.* (2002) recommend its use in primary care, as it not only assesses the severity of the symptom for the patient but also the distress that the symptom causes the caregiver. The carer is asked to rate the patients symptoms using a Likert scale of 1 = mild, 2 = moderate, 3 = severe. Similarly they are asked to rate their own level of distress for each symptom, 0 = 'no distress' to 5 = 'extreme distress', 'unable to cope with'. Higher scores indicate greater severity of the problem.

The COPE Index, used to assess carers' subjective perceptions of positive and negative aspects of their care-giving circumstances (McKee *et al.*, 2003). It is based on a theoretical model of informal care-giving of older people that addresses positive as well as negative aspects of care-giving (Nolan *et al.*, 1996; 1999). The COPE Index is notable for its brevity and simplicity, and its attempt to address both positive and negative aspects of the care-giving process. It directs attention to the quality of support the carer receives and this differentiates the Index from other brief assessment instruments developed for use with informal carers of older people which tend to focus only on negative aspects of the care-giving process. The Index takes approximately 10 minutes to complete.

The Carer’s Assessment of Difficulties Index (CADI), which was developed as a clinical tool for assessing the multiple dimensions of carer burden (Nolan and Grant, 1989). It has been used with a number of caring cohorts. Its ability to prompt carers to give descriptions of difficulties is of use to clinicians undertaking assessment with the intention of psycho-social intervention. The scale is sensitive to demographic characteristics such as carers’ age and gender (Charlesworth *et al.*, 2007).

The Satisfaction with Care at the End-of-Life in Dementia (SWC-EOLD), a validated scale that quantifies satisfaction with care in advanced dementia during the prior 90 days (Volicer *et al.*, 2001). The SWC-EOLD is a brief 10-item self-administered questionnaire, with each item measured on a four point Likert scale, ranging from 1 ‘strongly disagree’ to 4 ‘strongly agree’ (score range 10 - 40; higher scores indicating greater satisfaction). These items assess the caregiver’s level of satisfaction with decision-making, medical and nursing care, and their understanding of the condition of the person with dementia (Engel *et al.*, 2006).

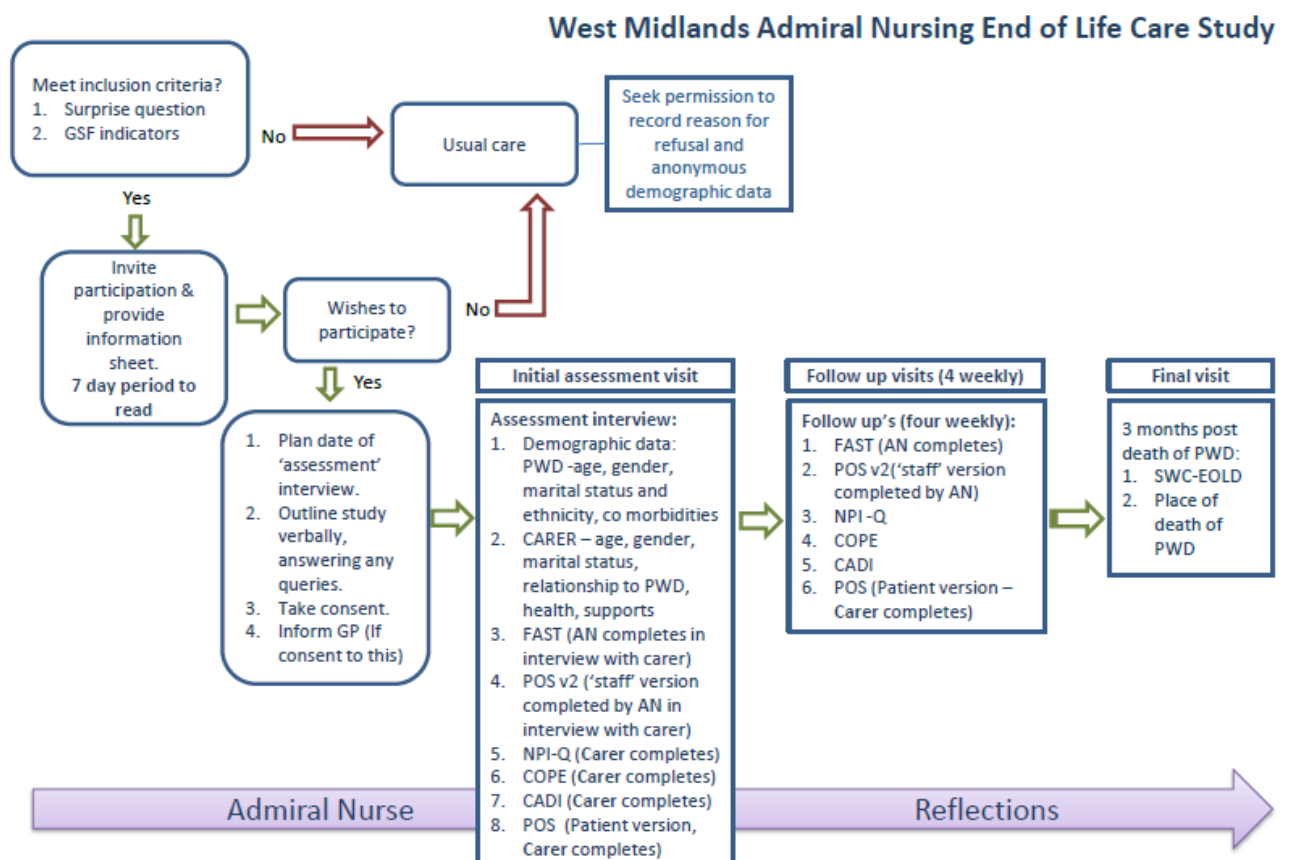


Figure One: Overview of recruitment and data collection

The aim was to complete these measures every four weeks for each participating dyad. If the person with dementia died during the study, the Admiral Nurse would visit the carer to explore how they are feeling/coping and assess need for bereavement support. This is part of routine Admiral Nurse practice. Three months after the death, the Admiral Nurses sought permission to send the carer the SWC-EOLD satisfaction with care at the end-of-life questionnaire. A diagrammatic representation of data collection is provided in figure one below.

The Findings

Participants and Data collection

As described above, the study planned to recruit participants from the caseload of two experienced Admiral Nurses. However, due to organisational and workload issues only one Admiral Nurse was able to fully engage with the project. By the time this became apparent it was too late to attempt to recruit another Admiral Nurse within the scope and resources of the project. In addition, recruiting participants from the target group was, as anticipated, challenging. As a result, this report is based on data collected from 4 dyads by one Admiral Nurse. This has obvious implications for the conclusions that can be drawn, both in terms of the amount of data on which they are based and the fact that they reflect the practice of a single Admiral Nurse. However, the quality of the data that was collected, particularly in the form of some very insightful reflective diaries, leads us to believe that the study retains considerable value as an in depth exploration of the role of Admiral Nursing towards the end of life.

Data were collected by the Admiral Nurse during (for the standard measures) and after (for the reflective diaries) visits to the dyads that took place between 7/3/12 and 27/12/13. A summary of the participants and the data collected is provided in Table 1 below.

Using standardised measures with people with dementia and their family carers

As table 1 suggests, experiences of using the standardised measures were mixed. Use of the Neuropsychiatric Questionnaire (NPI-Q), COPE Index and Carers Assessment of Difficulties Index (CADI) appears to be relatively successful across the four dyads. Implementation of the Palliative Care Outcome Scale (POS) was less successful, and the Satisfaction with End of Life Care in Dementia (SC-EOLD) tool was only appropriate for use with one dyad.

	Dyad 1	Dyad 2	Dyad 3	Dyad 4	
Participant Profiles					
Person with dementia (age, gender, marital status)	87 Male Married	79 Male Married	78 Male Married	80 Male Married	
Family Carer (age, gender, relationship)	52 Female Spouse	72 Female Spouse	74 Female Spouse	73 Female Spouse	
Data Collected					Totals
Reflective Diaries	12	9	2	2	25
Palliative Care Outcome Scale (POS)	2	7	0	0	9
Neuropsychiatric Questionnaire (NPI-Q)	9	7	1	2	19
COPE Index	8	7	1	2	18
Carers Assessment of Difficulties Index (CADI)	9	7	1	2	19
Satisfaction with End of Life Care in Dementia (SC-EOLD)	0	0	1	0	1
Totals	40	37	6	8	91

Table 1: Overview of participants and data collection

However, closer inspection of the data has revealed a more complicated picture in terms of the amount of data that could be collected using each tool. For example, many of the questions included in the NPI-Q were felt by the Admiral Nurse to be inappropriate to ask or did not elicit a clear answer, leading to a high level of missing data. In contrast, although the Palliative Care Outcome Scale (POS) was only appropriate for use with two of the four dyads, where it was used it was fully completed. It is important to bear these variations and limitations in mind when considering the following analysis.

The limitations of data collection as described above prevent us from carrying out any longitudinal analysis in relation to each measure. However, we are able to present selected findings based on aggregated data from all sessions carried out with each dyad.

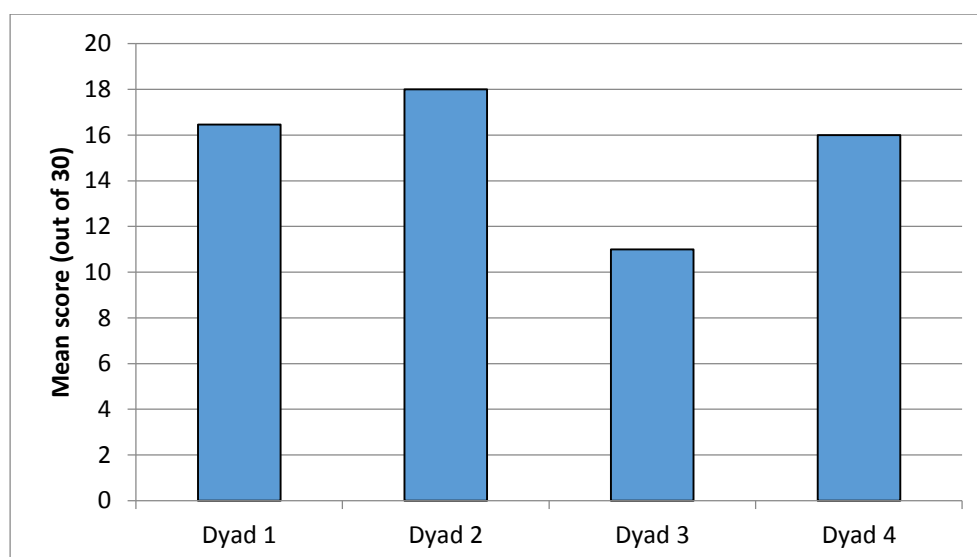


Figure 2. Carers Assessment of Difficulties Index: Presence of Stress

For example, figures 2 and 3 present scores from the Carers Assessment of Difficulties Index (CADI). This suggests that the CADI is able to detect differences in the presence and levels of stress for this group. Overall, the carer for dyad 3 appeared to be least stressed. The carer for dyad 1 experienced stress, but the level of stress was comparatively low (i.e. they did not appear to get overly stressed). Similarly, the Neuropsychiatric Inventory (NPI) (figure 4) appears to be sensitive to differences in behavioural symptoms.

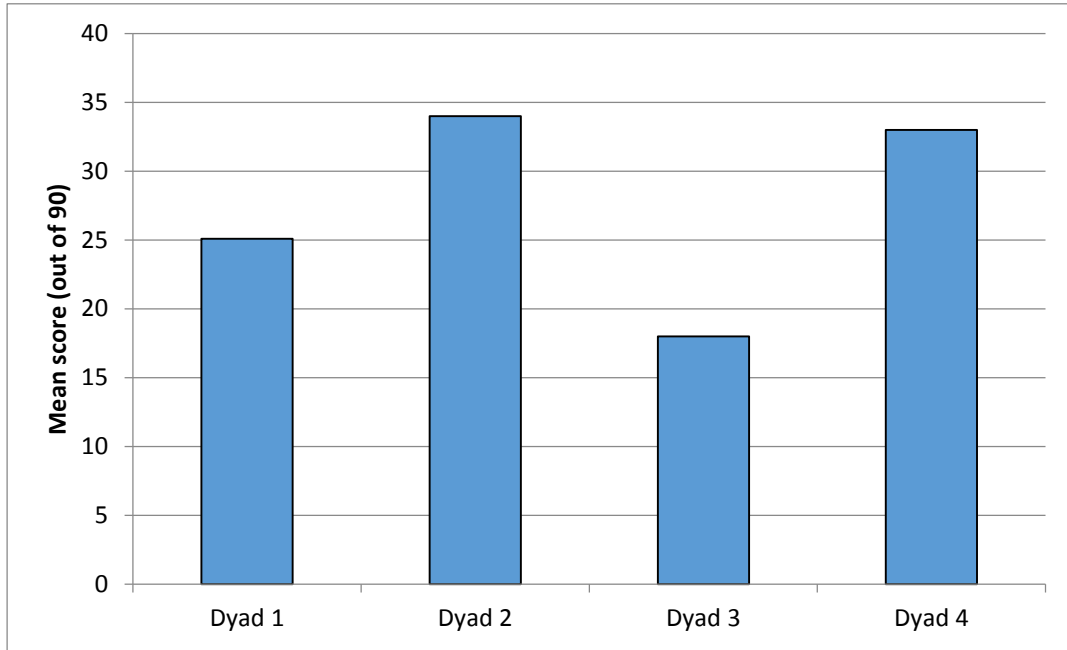


Figure 3. Carers Assessment of Difficulties Index: Levels of Stress

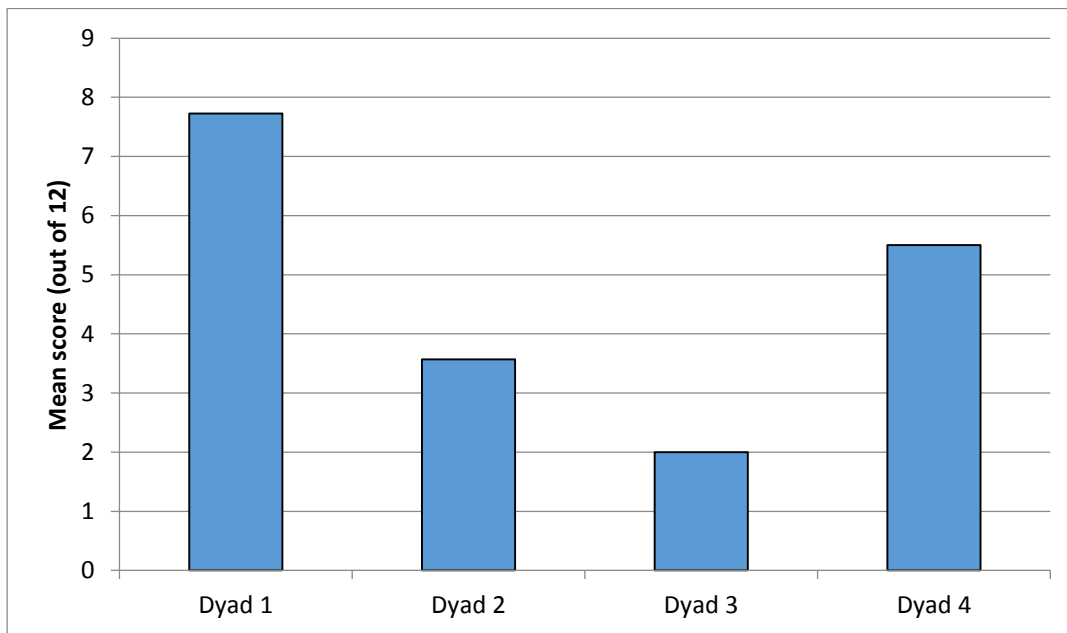


Figure 3. Figure Neuropsychiatric Inventory Questionnaire Behavioural Assessment - Severity of behaviour

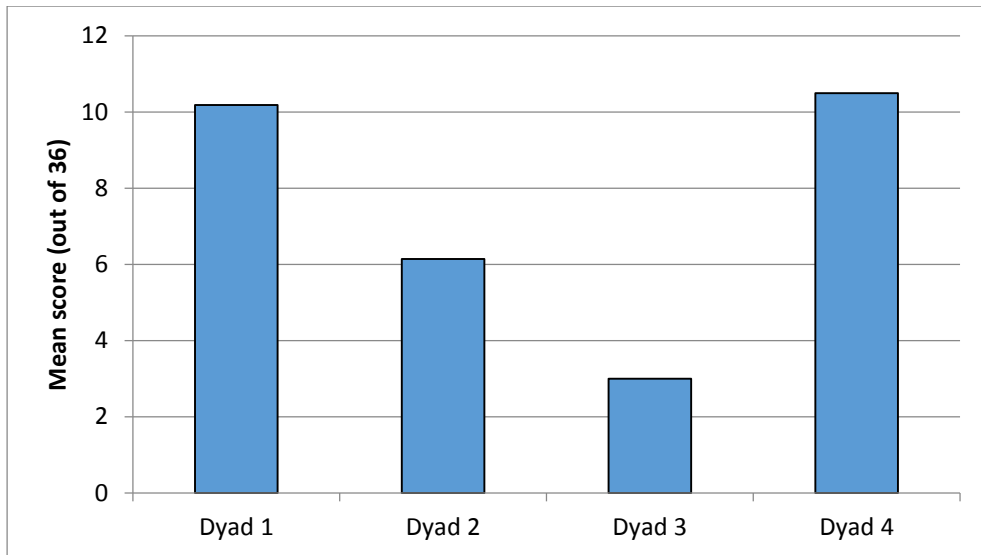


Figure 4. Neuropsychiatric Inventory Questionnaire Behavioural Assessment - Distress caused

These findings suggest that dyads 1 & 4 experienced more behaviours, but they had less of an impact in terms of distress caused. Dyad 2 experienced relatively few behaviours, but they caused more distress.

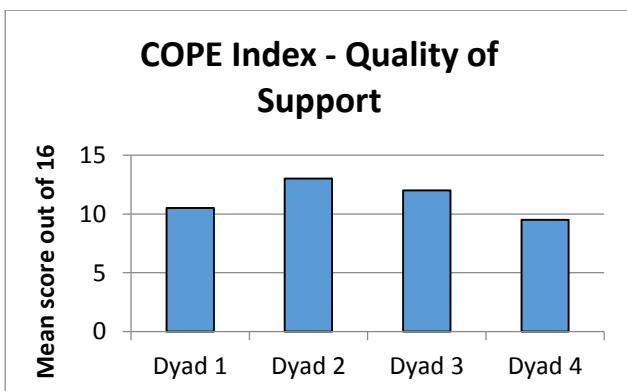
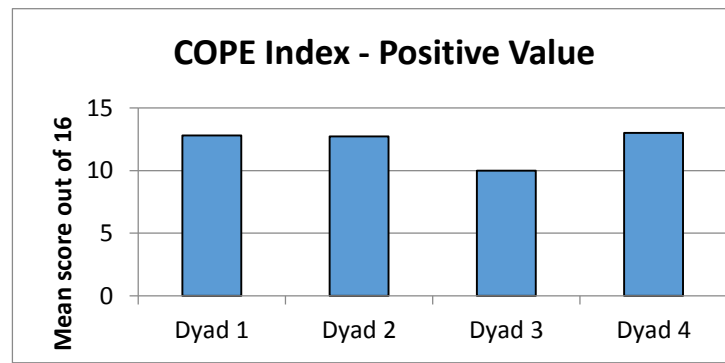
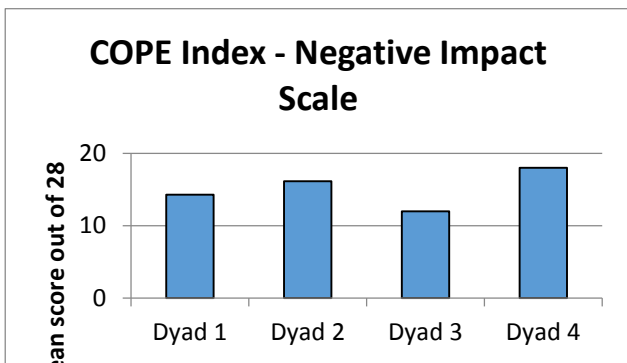


Figure 5. Scores from sub scales of the COPE Index

Data gathered using the COPE Index also exhibits considerable variation across the three subscales (figure 5). Analysis suggests that for Dyad 1, the carer reports low stress and high satisfaction but limited support; the Dyad 2 carer reports high stress and high satisfaction, along with high support; in Dyad 3 the carer reports low stress and low satisfaction, but good support; and the carer in Dyad 4 reports high stress and high satisfaction, but poor support. The limited amount of data does not support a more detailed analysis of these trends, but they do at least suggest that the measure has potential in this setting.

Reflective Diaries

The use of reflective diaries completed by the Admiral Nurse was successful and productive. Qualitative analysis of the diaries provides additional insight into the experiences of using the measures. Overall it is difficult to escape the conclusion that the measures are not appropriate for use in this setting, as the following quotes suggest.

'One aspect that is not included within the assessment tools is about considering the future and I have to be mindful of this in the session as part of the preventative and health promotion work is about planning ahead.'

'Again, as in previous sessions, I felt it would have been useful to have an assessment tool to enable me to formally assess X's wellbeing as the POS is not useful in his case.'

However, the Admiral Nurse did feel that some of the measures had value even where they were inappropriate for completion in full, largely as a way of facilitating discussion of difficult but important issues.

'I feel generally the COPE index and CADI helped me to address B's emotional needs as prior to undertaking this study, she would often deflect if I tried to explore this with her. By these needs being on a paper form almost 'gives permission' in a way to go into this emotional territory with B.'

'Although we did not utilise the POS, at each session we have referred to elements within that assessment to focus on X's physical symptoms. This enabled me to bring up the subject of resuscitation and whether the GP had completed the documentation for a DNACPR (Do not attempt cardiopulmonary resuscitation).'

The diaries also provide valuable insights into the experiences of family carers of people living with dementia at this stage in their illness. The sometimes overwhelming nature of this role is all too apparent, as the following quote suggests:

Although R is enjoying being able to go out with T again and get him involved with activities, she feels that care giving is too demanding at times and she commented that “it seems all encompassing” as T’s general abilities decline and his dependency seems to be increasing all of the time.

Similarly, there are indications of the impact of the caring role on a spouse, particularly in terms of opportunities for social interaction:

Her emotional wellbeing is suffering and not being able to keep in touch and see friends as often as she likes, she described her life as becoming “narrower”.

At the same time, there was a strong indication that the long-term nature of a relationship supports the caring role, particularly in the context of the emotional labour associated with it.

‘P recognises that caring for Q often has a negative effect on her emotional wellbeing but due to the fact that she has a good quality relationship with him, this gives her a great deal of positivity in her caring role and enables her to continue.’

There was also evidence of the skills and strategies that carers used in order to maximise the quality of life of the person with dementia in the face of changing abilities and behaviours.

It is evident from seeing S that he feels safe and secure with V and she has developed skilled communication strategies in minimising the behavioural and psychological symptoms that S experiences without the need for prescribed medication.

The caring role can also affect relationships with the wider family. One carer reported reduced levels of family contact as a result of the pressures of the caring role.

‘D finds that she doesn’t have enough private time for herself which is stressful, also the fact that her caring role can put a strain on her relationship with her family as she is not able to visit them as she would like and they do not keep in touch as often as she would like’

Other reasons mentioned for diminishing levels of contact include distance, the grief experienced by family members and family concerns for the wellbeing of the spouse who had taken on the caring role.

For one carer this led to considerable trepidation about how to manage family events:

She is still experiencing some difficulty in her relationship with her close family due to T's dementia and wonders how things will be when the family visits on Boxing Day and how she will be able to get them to acknowledge R when they visit and not to exclude him as she finds this very hurtful.

Our findings also provide insight into some of the effects that the Admiral Nursing role can have on those who perform it. The mixed emotions that can be triggered by this work are very apparent:

I felt both happy and sad during the session. My feeling of happiness came from witnessing how V puts so much energy into improving S' quality of life with involving him in the dramatized bible story at a local school. I also felt sad as significant changes are evident in S' general condition and V's acknowledgement that the situation is changing and that she is having to adjust to this new phase. I felt sad because I wonder how V is going to cope when S is no longer around. I reflect on my own situation of caring for my mother and I also wonder how I will feel when she is no longer around.

Also apparent is the strong sense of responsibility felt when trying to provide the best possible care and support for families at such a difficult time:

I feel a sense of responsibility in trying to address all aspects of care for both T & R so that we try and avoid crisis situations as much as possible. My thoughts today are thinking about how R will live her life after T dies as she has given up so much in order to devote herself to T.

I feel very responsible in my role to coordinate care and promote good communication channels between V, GP, District Nurse and hospice services.

It is not surprising that the role can also raise questions about the Admiral Nurse's own situation, as suggested in the following quote:

I thought of my own experience on a personal level and wondered whether I would be prepared to give up my career if this happened in my own life.

Another theme that emerges from the diaries is the importance of regular clinical supervision in order to address the high levels of emotional labour that are associated with the role.

End of life care for carer and person with dementia has an effect on me emotionally and I realise the importance of clinical supervision.

Discussion

Adaptation and coping

Performing a caring role can always be difficult, but care towards the end of life has been identified in this study as particularly so because the health of the person is an ever changing picture and carers face the double challenge of “adjusting to each new phase” and coming to terms with the final stages of the life of the person they love, sometimes without being able to discuss this in a meaningful way with their spouse as their cognitive symptoms also progress. At the same time carers in this study also recognised that there was an additional background concern of: “will/how will I cope when my spouse is no longer here?”

Strategies carers found helpful and assisted them to cope well included:

- Reliable and consistent support
- Professional with skills to provide openings to enable emotional needs to be aired
- Support from a wider healthcare team
- Enabling the carer to have the information they felt they needed and could take in, which in turn provided the carer with a sense of control
- Supporting carers to develop skilled communication strategies, which minimised the behavioural and psychological symptoms in the person with dementia. This promoted wellbeing and a continuing positive relationship between the person and their carer

Emotional labour and emotional rewards

There were tremendous positives for the nurse involved in being able to spend time with both the person with dementia and their carer and to share moments of humour and to witness the person in a state of wellbeing and the person with dementia and their carer share moments of fun together. Seeing a carer put huge energy into improving quality of life was re-affirmatory. However the role also involves experiencing and acknowledging the distress felt by a carer and understanding that this is exacerbated when the person they care for becomes tearful and low.

The impact on family carers

Whilst the role of caring has both emotional satisfaction and challenges the study also demonstrated the risks posed to the physical health of carers in addition to stress on their sense of wellbeing and identity.

This study has also reinforced the value which the carer places on having the opportunity to maintain a close and loving relationship and the quality of that relationship is highly significant in supporting carers to adapt to aspects of their role changing and finding strategies to continue to express that relationship. The feelings of love for the person they are caring for are key to keeping the care giver's wellbeing, however the dementia combined with their other health problems makes it less likely that the person can continue to express that love in the ways familiar to both parties. The importance of the support of a skilled professional to enable the carer to reflect and go forward, sometimes without the sustenance of demonstrable reciprocity of love was demonstrated within the study.

Relationships with families

Family and friends are regarded as one of the key supports at times of crisis and particularly as a loved one moves towards the end of their life. However the people supported in this study found that extended family and often close friends did not always provide the support they would have wished for. Indeed the role of caring for someone with dementia appeared to put additional distance between them and their family which added to the stress of the situation. Part of the professional role was to help carers put this into some perspective which enabled them to cope with this additional loss and also to find

strategies to find support and respite from other sources. Gaining an understanding of the grief felt by their children when their father's dementia developed helped a carer to maintain her relationship with them. The study also highlighted the importance of supporting the carers to maintain family relationships, even when disappointed by their apparent lack of support during the last year of the person's life, family support may re-emerge when the carer is living on their own and this support is also valuable.

Relationships with professionals

In many instances comorbidities add to the complexity of the professional team providing the support package. Providing care for someone nearing the end of their life who has dementia and limited insight or ability to help themselves challenges the resources of carers and compounds a sense of being alone with the problems. Part of the role of the Admiral Nurse is to advocate with fellow professionals and to work therapeutically with the carer so that they feel able to continue their caring role.

The study identified the importance of coordinating care and promoting good communication channels between carer and person with dementia and their GP, District Nurse, specialist nurses and hospice services. Communication between the carer and the care home is another complex area requiring skilled intervention and advocacy.

There was evidence within the study of carers feeling empowered and having positive experiences with specialist professionals who were able to provide them with support and information. The role of the Admiral Nurse was in part to predict which services might be needed in the next step of the journey and promote confidence in the carer by helping them to feel prepared and knowledgeable about options and systems.

Social interaction

Dementia is known to reduce opportunities for social interaction; however this is exacerbated when the person with dementia is experiencing significant symptoms from a comorbid condition. The resultant tiredness, apathy and indifference is difficult to adapt to, particularly if out of character. One of the key impacts is that the social life previously experienced as a couple reduces and the carer has neither energy nor opportunity to recreate social engagement their own right, thus the couple feel more isolated. Emotional

wellbeing may suffer as a consequence of being unable to keep in touch and life becomes “narrower”. Tiredness is a significant factor.

One of the factors which contribute to the social isolation of someone with dementia and by association their spouse is the lack of understanding of the symptoms of dementia and how those might be expressed. This lack of awareness can extend to family members and an increasingly important role of promoting awareness is crucial in enabling families to be supportive and not to avoid the person or exclude them, which is distressing both for them and their spouse.

There were humbling examples within the study of carers going to extraordinary lengths to ensure that the person they loved had opportunities for social engagement in a context that was deeply meaningful for them, both socially and spiritually. It was clear that achieving this and seeing the evidence of the enhanced wellbeing of their loved one added greatly to the satisfaction of the caring role. Enabling carers to see and have the energy to take such opportunities may make a significant impact.

Likewise seeing a professional’s visit as an opportunity to enhance the wellbeing of the person with dementia in addition to working therapeutically with the carer has additional benefits for all parties.

The role of the Admiral Nurse

This study has provided useful insight into the nature of the Admiral Nursing role and some of the factors that make it effective. A carer of a person with dementia coming towards the end of their life may be faced with a range of complex and emotive decisions which given their isolation they may find hard to make or equally may need to be assertive to ensure that the needs of their loved one remain paramount. Facilitating an exploration of the carer’s worst fears and best hopes is a highly sensitive piece of work but hugely important in planning for the end of the person’s life and putting in place strategies to support the aspirations. Advance care planning plays a part in reducing the tension of this and confidence in discussing this and ensuring that plans are drawn up appropriately is an important aspect of the role. The knowledge and abilities of a highly skilled professional

such as an Admiral Nurse are an important factor in ensuring that carers are empowered with confidence and knowledge and on occasion when the carer is too stressed or exhausted may be required to act as advocate to ensure that the carer is able to exercise the control and decision making function appropriate to their role in the life of their loved one.

The Admiral Nurse will maintain a focus on the impact that caregiving is having on the carer, directly addressing changes to the carer's emotional and physical health and interventions that may be needed to improve these. Training in advanced communication skills is important, alongside reflective practice and effective clinical supervision is an essential component to underpin practice in this area.

The issue of enabling the carer to look to the future is a complex one. Carers put a great deal of investment into caring for the person they love and frequently have given up a great deal to care for that person but at some time in the near future the person will die and they will have to face a life without them. The all-embracing care role when someone has dementia and is nearing the end of their life leaves little time for preparation for that eventuality; but the value of preparation to support adjustment is well evidenced.

Impacts on the Admiral Nurse

Working with people and their families when they are approaching the end of life is an emotional experience for the professionals involved too. The study brought up numerous examples of shared sadness but also moments of joy. The nurse involved in the study readily identified that it was a privilege to be able to witness the strength of love in relationships and also the shared moments of fun which brought a sense of wellbeing to the person with dementia.

The study also identified the importance of the professional's emotional self-awareness, particularly when the situations that the professional is engaged in therapeutically are paralleled in their own family. The practitioner needs to be aware of the impact that their professional experiences may have on their personal emotions and also of potential transference between their personal experience and the professional situations in which they are therapeutically engaged.

This is an important role and much needed, but requires emotional intelligence and resilience. It requires a strongly reflective practitioner supported by effective clinical supervision.

The use of standardised measures

There is always a concern that using tools/measures/documentation to support practice runs a risk of becoming a barrier to relationship building and may constrain the therapeutic engagement to the focus of the measure and distract from the key issues that a carer needs to explore. However it appears that some of the tools used within the context of a therapeutic relationship may be helpful in drawing out issues which might otherwise be overlooked by the carer or professional supporting them. There was an acknowledged benefit to some carers who found the application of the measures created a sense of control for them which then enabled them to open up and express emotional needs. The nurse recognised the value of utilising the assessment tools because “at face value A presented as happy and relaxed and I might not have gained much else had I not utilised these tools and we would have missed an opportunity to discuss in detail the impact of B’s changing condition and A’s response to this.” Thus the use of tools reduces the risk of nurses or other professionals overlooking aspects of caring or avoiding use of interventions that are challenging for them as well as the carer.

Carers in the midst of caring for someone they love who is coming to the end of their life will usually be focused on that person; the assessment tools enabled a focus on the impact of caring including the carers’ own physical, emotional and psychological needs and to address areas that might not otherwise have been addressed, for example the emotional impact and how relationships influence the experience of caring.

Specific measures highlighted and provided insight into specific aspects of the caring role and the impact which it has. The nurse in the study felt that some of the tools (CADI, COPE & NPI) when accompanied by enhanced communication skills were a productive use of clinical time and facilitated a speedier formulation of issues in caring experienced by each carer. They enabled different facets of the caring experience, including emotional and relational aspects, to be addressed in a structured and focused way which appeared comfortable to the carers.

The COPE index highlighted the extent of emotional and physical impact on carer both in the present and over time. It enabled consideration of sources of support and perception of the quality of that support and prompted reflection on the profound impact dementia has on relationships with friends and family. Likewise, the CADI proved helpful in identifying the strain which the caring role put on relationships with friends and family.

CADI was particularly useful in identifying broader issues of emotional stress and prompting discussion on the challenge of feeling helpless, being unable to maintain control and of being trapped within the situation. Use of the CADI was helpful in identifying the impact of the therapeutic relationship in supporting adaptation to change over time which was particularly helpful in enabling a carer to see the impact of plans which enabled her to have a greater sense of well-being and increased coping skills.

Reviewing the outcomes of the measures with each carer was of considerable therapeutic benefit, enabling them to have a sense of control and collaboration and helped the carer and nurse to make sense together of what was happening in the carer's current experience.

There was an additional benefit in using COPE and CADI together as the responses on occasion threw up contradictions which enabled the nurse to explore in greater depth the potential issues raised. One poignant example was one of the carers who in exploring responses came to an understanding that aspects of her relationship with her husband had changed considerably and that whilst she felt the relationship continued to be good she found it hard that he was unable to reciprocate any feelings of love and appreciation in the ways he had previously done. It is probable that without the differences in response across the two measures she would have continued to maintain that all was well and an important therapeutic opportunity would have been missed.

The NPI had less impact as a tool but did help to identify when the person with dementia began to experience more distress with behavioural and psychological symptoms and the impact that had on the carer. This was also helpful in prompting review of the person's symptom's, pain, and discomfort and also identification of potential factors creating anxiety.

Although the POS was not found to be helpful in its entirety, reference to elements within that assessment may support a focus on physical symptoms experienced by the person with dementia, enabling discussion re resuscitation and process for completion of documentation such as DNACPR (Do not attempt cardiopulmonary resuscitation). This is a difficult area to address and it would be helpful to have available a specific assessment tool for a person with dementia that encompasses both the behavioural and psychological impact and also the physical health aspects in the last months of their life. A tool which incorporates the NPI, wellbeing and physical symptoms would offer a more holistic approach.

The other aspect not considered within the assessment tools used in this study was a tool which supports consideration of the future, both for the person with dementia at the end stages of their life and also for the ongoing life of the carer. This is a significant area of practice which could be addressed with greater focus as it was an area which carers acknowledged they found hard to voice. Therapeutically this was an important area of work, enhanced by the combination of effective communication and sensitive application of some of the measures.

Use of the tools within therapeutic practice enhanced the empathic understanding which the nurse had built up over time. This is highly skilled work requiring a reflective practitioner with strong communication skills. The impact of this role should not be underestimated and support systems need to be robust.

Conclusion

This small in depth study has provided unique insights into the role of Admiral Nurses who provide care and support towards the end of life. Within this context the findings provide valuable information about the potential impacts of Admiral Nursing on family carers and on the Nurses themselves, as well as describing the practical experiences of using a range of standardised measures.

Overall, the findings bear witness to the highly skilled and sensitive nature of Admiral Nursing, with its focus on facilitating exploration of carer's worst fears and best hopes. This

role plays a hugely valuable part in planning for the end of the person's life and putting in place strategies to support aspirations. In this respect the Admiral Nursing service aligns closely with national and international policy for dementia, multimorbidity and end of life care.

Admiral Nurses empower family carers in many ways including supporting coping, promoting adaptation and providing a link with a range of other health and social care professionals. It is important not to underestimate the impacts of the role on Admiral Nurses themselves. This study confirms the high levels of emotional labour that can result from performing such an intensive role, while also revealing some of the emotional rewards. The findings highlight some of the skills that lie at the heart of Admiral Nursing, which include advanced communication skills, reflective practice and emotional self-awareness. Comprehensive training in these areas and effective clinical supervision are essential to underpinning effective and sustainable practice.

Another important aim of this study was to explore the use of a range of standardised measures to support Admiral Nursing towards the end of life. We uncovered some concerns that this approach can be a barrier to relationship building and may constrain therapeutic engagement. However, at the same time there is evidence that some of the tools used within the context of a therapeutic relationship may be helpful in drawing out issues which might otherwise be overlooked by the carer or professional supporting them. For example, some assessment tools enabled a focus on the impact of caring including the carers' own physical, emotional and psychological needs. Tools such as CADI, COPE & NPI appear to have the potential to enable different facets of the caring experience, including emotional and relational aspects, to be addressed in a structured and focused way which appeared comfortable to the carers. There may also be additional benefit in using COPE and CADI together as the responses on occasion threw up contradictions which enabled the nurse to explore in greater depth the potential issues raised. In this study the NPI had less impact as a tool, although it did help to identify when the person with dementia began to experience more distress with behavioural and psychological symptoms and the impact that had on the carer. Although the POS was not found to be helpful in its entirety, reference to elements within that assessment may support a focus on physical symptoms experienced by the person with dementia, enabling discussion re resuscitation and process for completion of documentation such as DNACPR (Do not attempt cardiopulmonary

resuscitation). However, we conclude that it would be helpful to have available a specific assessment tool for a person with dementia that encompasses both the behavioural and psychological impact and also the physical health aspects in the last months of their life. A tool which incorporates the NPI, wellbeing and physical symptoms would offer a more holistic approach.

In addition, we suggest that there is a need for a tool which supports consideration of the future, both for the person with dementia at the end stages of their life and also for the ongoing life of the carer.

References

- Adamis, D., Martin, F.C., Treloar, A., & Macdonald, A.J. (2005) Capacity, consent, and selection bias in a study of delirium. *J.Med.Ethics*, 31, (3) 137-143 available from: PM:15738432
- Addington-Hall, J. (1998). *Reaching out; specialist palliative care for adults with non-malignant diseases*. In : National Council for Hospice and Specialist Palliative Care Services.
- AHLUWALIA, S.C., GROSS, C.P., CHAUDRY, S.I., LEO-SUMMERS, L., VAN NESS, P.H. & FRIED, T.R. (2011) Change in Comorbidity Prevalence with Advancing Age Among Persons with Heart Failure. *Journal of General Internal Medicine*, 26 (10):145-51.
- Ahronheim, J. C., Morrison, R. S., Morris, J., Baskin, S. and Meier, D. E. (2000). Palliative care in advanced dementia: a randomized controlled trial and descriptive analysis. *Journal of Palliative Medicine*.3(3):265-73, 2000 Fall.(23 ref), 265-273.
- Alzheimer's Society (2009) *Counting the Cost: Caring for people with dementia on hospital wards*. Alzheimer's Society: London.
- Aspinal F, Hughes R, Higginson I, Chidgey J, Drescher U, Thompson M (2002) A user's guide to the Palliative care Outcome Scale. King's College London.
- BOYD, C.M. & FORTIN, M. (2010) Future of Multimorbidity Research: How Should Understanding of Multimorbidity Inform Health System Design? *Public Health Reviews*, 32: 451-474.
- BUNN, F., PINKNEY, E., DRENNAN, V. & GOODMAN, C. (2013) *An evaluation of the role of the Admiral Nurse: a systematic evidence synthesis to inform service delivery and research*, Dementia UK Report: Unpublished Internal report.
- BURTON, J. & HOPE, K.W. (2005) An exploration of the decision-making processes at the point of referral to an Admiral Nurse team. *Journal of Psychiatric Mental Health Nursing*, 12 (3): 359-364.
- CIGOLLE, C.T., LANGA, K.M., KABETO, M.U., TIAN, Z. & BLAUM, C.S. (2007) Geriatric conditions and disability: the Health and Retirement Study. *Annals of Internal Medicine*, 147 (3): 156-164.
- Charlesworth G.M., Tzimoula X.M., and Newman S. P. (2007) Carers Assessment of Difficulties Index (CADI): Psychometric properties for use with carers of people with dementia. *Aging & Mental Health*, 11(2): 218–225.
- CRONIN-STUBBS, D., BECKETT, L.A., SCHERR, P.A., FIELD, T.S., CHOWN, M.J., PILGRIM, D.M, BENNETT, D.A. & EVANS, D.A. (1997) Weight loss in people with Alzheimer's disease: a prospective population based analysis. *BMJ*, 314 (7075): 178-179.
- Cummings JL, Frank JC, Cherry D, Kohatsu ND et al (2002) Guidelines for Managing Alzheimer's Disease: Part1. Assessment. *American Family Physician*, 65:11, 2263-2002).
- DAVIES, E. & HIGGINSON, I.J. (2004) *Better Palliative Care for Older People: Report*, World Health Organisation Europe.

Department of Constitutional Affairs (2005) *Mental Capacity Act*.

DH (2008) *End-of-Life Care Strategy*, London: Department of Health.

DH (2009) *Living Well with Dementia: A National Dementia Strategy*, London: Department of Health.

DORAISWAMY, P.M., LEON, J., CUMMINGS, J.L., MARIN, D. & NEUMAN, P.J. (2002) Prevalence and impact of medical comorbidity in Alzheimer's disease. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57 (3): M173-177.

Engel SE, Kiely DK and Mitchell SL (2006) Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. *JAGS*, 54: 1567-1572.

ERIKSSON, S., STRANDBERG, S., GUSTAFSON, Y. & LUNDIN-OLSSON, L. (2008) Circumstances surrounding falls in patients with dementia in a psychogeriatric ward. *Archives of Gerontological Geriatrics*, 49 (1): 80-87.

FELDT, K.S., WARNE, M.A. & RYDEN, M.B. (1998) Examining pain in aggressive cognitively impaired older adults. *Journal of Gerontological Nursing*, 24 (11): 13-22.

FOLEY, K.M. & CARVER, A.C. (2001) Palliative care in neurology. *Neurologic Clinics*, 19 (4): 789-799.

Forester BP, and Oxman TE (2003) Measures to Assess the Noncognitive Symptoms of Dementia in the Primary Care Setting. *Primary Care Companion J Clin Psychiatry*, 5:158-163.

Freedberg DE, Dave J, Kurth T, Gaziano JM and Bludau JHA (2008) Cognitive impairment over the age of 85: hospitalization and mortality. *Archives of Gerontology and Geriatrics*. 46: 137-45.

FROGGATT, K., McCORMACK, B. & REED, J. (2006) End-of-life issues in long-term care - implications for practice. *International Journal of Older Peoples Nursing*, 1 (1): 44, doi: 10.1111/j.1748-3743.2006.00011.x.

G8 HEALTH & SCIENCE MINISTERS (2013) G8 Global Action Against Dementia: Dementia Summit Declaration.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/265869/2901668_G8_De mentiaSummitDeclaration_acc.pdf

Gibbs (1988) *Learning by Doing: A guide to teaching and learning methods*. Further Education Unit, Oxford Brookes University, Oxford

Hanrahan, P., Raymond, M., McGowan, E. and Luchins, D. J. (1999). Criteria for enrolling dementia patients in hospice: a replication. *American Journal of Hospice & Palliative Care*.16(1):395-400, 1999 Jan-Feb.(7 ref), 395-400.

HARRIS, S., HO, D. & VERNE, J. (2010) *Deaths from Alzheimer's disease, dementia and senility in England*. Bristol: National End of Life Care Intelligence Network.

- HARRISON DENING, K. (2010) Admiral Nursing: offering a specialist nursing approach. *Dementia Europe*, 1: 10-11.
- House of Commons Health Committee (2005). *Palliative Care*. In : The Stationary Office Limited.
- ILIFFE, S. (2013) Commissioning services for people with dementia: how to get it right. *The Psychiatric Bulletin*, 37: 121-123.
- Kaufer DI, Cummmings JL, Ketchel P, Smith V, Macmillan A (2000) Validation of the NPI-Q, a Brief Clinical Form of the Neuropsychiatric Inventory. *Journal of Neuropsychiatry Clinical Neuroscience*, 12: 233-239.
- KEADY, J., ASHCROFT-SIMPSON, S., HALLIGAN, K. & WILLIAMS, S. (2007) Admiral nursing and the family care of a parent with dementia: using autobiographical narrative as grounding for negotiated clinical practice and decision-making. *Scandinavian Journal of Caring Sciences*, 21 (3): 345-353.
- Kivipelto M, Helkala E, Laakso MP, Hänninen T, Hallikainen M, Alhainen K, Soininen H, Tuomilehto J and Nissinen A (2001) Midlife vascular risk factors and Alzheimer's disease in later life: longitudinal, population based study. *BMJ*. 322: 1447-1451.
- Kivipelto M, Ngandu T, Fratiglioni L, Viitanen M, Kåreholt I, Winblad B, Helkala E, Tuomilehto J, Soininen H and Nissinen A (2005) Obesity and Vascular Risk Factors at Midlife and the Risk of Dementia and Alzheimer Disease. *Archives of Neurology*. 62:1556-1560.
- Knapp, M. and Prince, M. (2007). *Dementia UK: The Full Report*. In London: Alzheimer's Society.
- KULMALA, J., NYKANEN, I., MANTY, M. & HARTIKAINEN, S. (2014) Association between Frailty and Dementia: A Population-Based Study. *Gerontology*, 60 (1): 16-21.
- McKee K. J., Philip I., Lamura G., Prouskas C., Berg B. O, Krevers B., Spazzafumo L., Bien B., Parker C., Nolan M. R. and Szczerbinska K. on behalf of the COPE Partnership (2003) The COPE index—a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people, *Aging & Mental Health*, 7(1): 39–52.
- Maletta, G. J. (1995). Access to hospice programs in end-stage dementia. *Journal of the American Geriatrics Society*, 43(10), 1174-1175.
- MARENGONI, A., ANGLEMAN, S., MELIS, R., MANGIALASCHE, F., KARP, A., GARMAN, A., MEINOW, B. & FRATIGLIONI, L. (2011) Aging with multimorbidity: a systematic review of the literature. *Ageing Research Reviews*, 10 (4): 430-439.
- MARTYN, C.N. & PIPPARD, E.C. (1998) Usefulness of mortality data in determining the geography and time trends of dementia. *Journal of Epidemiology and Community Health*, 42: 134-137.
- MITCHELL, S.L., KIELY, D.K. & HAMEL, M.B. (2004) Dying with advanced dementia in the nursing home. *Archives of Internal Medicine*, 164 (3): 321-326.

MITCHELL, S.L., TENO, J.M., KIELY, D.K., SHAFFER, M.L., JONES, R.N., PRIGERSON, H.G., VOLICER, L., GIVENS, J.L. & HAMEL, M.B. (2009) The Clinical Course of Dementia. *New England Journal of Medicine*, 361 (16): 1529-1538.

MORGAN, K. & CLARKE, D. (1995) To what extent is dementia underreported on British death certificates? *International Journal of Geriatric Psychiatry*, 10 (11): 987-990.

MORRISON, R.S. & SIU, A.L. (2000) Survival in end stage dementia following acute illness. *Journal of the American Medical Association*, 284 (1): 47-52.

Neale, R., Brayne, C. and Johnson, A. L. (2001). Cognition and survival: an exploration in a large multicentre study of the population aged 65 years and over. *International Journal of Epidemiology*, 30, 1383-1388.

Nolan, M. R., & Grant, G. (1989). Addressing the needs of informal carers: A neglected area of nursing practice. *Journal of Advanced Nursing*, 14, 950–961.

Nolan M., Grant G. and Keady J. (1996). *Understanding family care: a multidimensional model of caring and coping*. Buckingham: Open University Press.

Nolan M. and Philip I. (1999). COPE: towards a comprehensive assessment of caregiver need. *British Journal of Nursing*, 8, 1364–1372.

Office for National Statistics (2005). *Focus on Older People*. In London: The Stationary Office.

O'Rourke N and Tuokko HA (2003) Psychometric Properties of an Abridged Version of the Zarit Burden Interview Within a Representative Canadian Caregiver Sample. *The Gerontologist*, 43:1, 121-127.

PRINCE, M., ACOSTA, A., FERRI, C.P., GUERRA, M., HUANG, Y., JACOB, K.S., JOTHEESWARAN, A.T., LIU, Z., RODRIGUEZ, J.J., SLAS, A.L. & WILLIAMS, J.D. (2011) The association between common physical impairments and dementia in low and middle income countries, and, among people with dementia, their association with cognitive function and disability. A 10/66 Dementia Research Group population-based study. *International Journal of Geriatric Psychiatry*, 26 (5): 511-519.

Reisburg B (1988) Functional assessment staging (FAST). *Psychopharmacology Bulletin*, 24: 653-659.

Rice, K. and Warner, N. (1994). Breaking the bad news: what do psychiatrists tell patients with dementia about their illness? *International Journal of Geriatric Psychiatry*, 9, 467-471.

RENÉ, J.F., MARENGONI, A., RIZZUTO, D., TEERENSTRA, S., KIVIPELTO, M., ANGLEMAN, S.B. & FRATIGLIONI, L. (2013) The Influence of Multimorbidity on Clinical Progression of Dementia in a Population-Based Cohort. *PLOS One*, 8 (12): e84014.

Rusanen Rovio Ngandu T, Nissinen A, Tuomilehto J, Soininen H and Kivipelto M (2010) Midlife smoking, Apolipoprotein E and risk of dementia and Alzheimer's Disease: A population-based cardiovascular risk factors, aging and dementia study. *Dementia & Geriatric Cognitive Disorders*. 30(3) 277-284.

Sampson, E. L., Ritchie, C. W., Lai, R., Raven, P. W. and Blanchard, M. R. (2005). A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics*. 17: 31-40.

Sampson EL, Blanchard MR, Jones L et al. (2009) Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *The British Journal of Psychiatry*. 195: 61–66.

SAMPSON, E. L. & HARRISON DENING, K. (2013) Palliative care and end of life care. In: *Oxford Textbook of Old Age psychiatry*, 2nd edition, DENING, T. & THOMAS, A. (editors) Oxford: Oxford University Press.

TSCHANZ, J.T., CORCORAN, C., SCHOOOQ, I., KHACHATURIAN, A.S., HERRICK, J., HAYDEN, K.M., WELSH-BOHMER, K.A., CALVERT, T., NORTON, M.C., ZANDI, P. & BREITNER, J.C. CACHE COUNTY STUDY GROUP (2004) Dementia: The leading predictor of death in a defined elderly population: the Cache County Study. *Neurology*, 62 (7): 1156-1162.

VAN DEN AKKER, M., BUNTINX, F. & KNOTTNERUS, J.A. (1996) Comorbidity or multimorbidity: What's in a name? *European Journal of General Practice*, 2: 65-70.

VAN DER STEEN, J.T., RADBRUCH, L., HERTOOGH, C.E.M., DE BOER, M.E., HUGHES, J.C., LARKIN, P., FRANCKE, A.L., GOVE, D., FIRTH, P., KOOPMANS, R.T. & VOLICER, L. (2013) White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, 28 (3):197-209.

Volicer L, Hurley AC and Blasi ZV (2001) Scales for Evaluation of End-of-Life Care in Dementia. *Alzheimer Disease and Associated Disorders*, 15:4, 194-200.17, 31-40.

Midlife cardiovascular risk factors and risk of dementia in late life. *Neurology*. 64:277-281.

WILCOCK, J., FROGGATT, K. & GOODMAN, C. (2008) End of Life Care. In: DOWNS M. & BOWERS, S. (editors) *Excellence in Dementia Care: Research into Practice*, Maidenhead: Open University Press.

WOODS, R.T., WILLS, W., HIGGINSON, I.J. & WHITBY, M. (2003) Support in the community for people with dementia and their carers: a comparative outcome study of specialist mental health service interventions. *International Journal of Geriatric Psychiatry*, 18: 298-307.

World Health Organisation (1990). *Cancer Pain Relief and Palliative Care*. In Geneva.

www.goldstandardsframework.nhs.uk/content/gp_contract/Prognostic%20Indicators%20Guidance%20Paper%20v%2025.pdf (date last accessed 11/02/11)

www.goldstandardsframework.nhs.uk/content/non_cancer/suggested_prognostic_indicators_of_advanced_disease.pdf (date last accessed 11/02/11)

XIE, J., BRAYNE, C. & MATTHEWS, F.E. (2008) Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ*, 336 (7638): 258-262.

ZULIANI, G., GALVANI, M., PRANDINI, S., BOARI, B., GUERZONI, F. & GALLARANI, M. (2011)
Discharge diagnosis and co morbidity profile in hospitalized older patients with dementia.
International Journal of Geriatric Psychiatry, 27 (3): 313-20.

Appendix 1: The Mental Capacity Act (2005)

People who lack capacity

The principles: Chapter 9, part 1, no 1.

A person is assumed to have capacity unless demonstrated otherwise.

All practical steps must be taken to help a person make a decision before deciding he cannot do so.

An unwise decision per se does not show lack of capacity.

An act done on behalf of someone who lacks capacity must be done in his best interests.

Before such an act is done, consider whether the purpose can be achieved by means less restrictive to the person's rights and freedom of action.

The project Admiral Nurse will assess the person with dementia's capacity to make a decision regarding their consent to participate in the study. The 'functional' test of capacity, adapted from the common law by the Mental Capacity Act (2005) which focuses on the decision-making process itself will be used to determine the person's capacity. Under the Act, a person is regarded as being unable to make a decision if, at the time the decision needs to be made, he or she fails:

to understand the information relevant to the decision.

to retain that information.

to use or weigh that information as part of the process of making the decision.

to communicate the decision (by any means)

Where an individual fails one or more parts of this test, then they do not have the relevant capacity and the entire test is failed (MCA chapter 9, part 1, no 3)

If a person is not competent to be involved in decisions regarding participation in the study, consent to the person with dementia's participation in the study will be sought from the LPA, or person nominated by the person lacking capacity e.g. legal next of kin/main carer, if LPA is not yet registered.

Appendix 2: Protocols to safe guard the person with dementia and the carer

Protocol to safeguard the person with dementia

The Admiral Nurse will at all times ensure that the information given to the person with dementia is presented in a format that is sensitive and appropriate to their needs.

If at any time the person with dementia declines to answer routine information or assessment questions, this will be respected and no further attempts to obtain the information will be sought directly from the person at that time.

The person with dementia (who has capacity) will be asked if they give permission for information to be obtained from their main carer.

If the person with dementia shows any sign of distress before or during the assessment then the Admiral Nurse will attempt to ascertain the cause of distress if possible e.g. if the person is in pain and appropriate intervention will be given.

If the person with dementia is upset following the assessment the carer will try to elicit the cause of upset if possible e.g. was it related to any part of the assessment?

The carer will be asked to report this to the Admiral Nurse.

Protocol to safe guard carer:

The Admiral Nurse will at all times ensure that the information given to the carer is presented in a format that is sensitive and appropriate to the carers needs.

If at any time the carer declines to answer routine information, assessment questions or complete questionnaires, then this will be respected and recorded.

If the carer shows any sign of discomfort or distress in answering questions or completing questionnaires, then the Admiral Nurse will stop the assessment. The assessment will only be continued if the carer feels comfortable to continue.

If the carer scores between 21-40 or above on the Carer Burden Questionnaire then this will be discussed sensitively with the carer and, as per the working model of Admiral Nursing, advice/support will be tailored to meet needs/issues identified.

Appendix 3: The Research Measures

Functional Assessment Staging (FAST)

FUNCTIONAL ASSESSMENT STAGING (FAST)

* Check highest consecutive level of disability:

Fast stage	CHARACTERISTICS
1	No functional decline.
2	Personal awareness of some functional decline.
3	Noticeable deficits in demanding job situations.
4	Requires assistance in complicated tasks such as handling finances, planning dinner for guests, etc.
5 a - - b	Cannot recall, address, telephone number, family members' name. Frequently some disorientation to time or place. Cannot do serial 4s from 40, or serial 2s from 20.

<p>--</p> <p>c</p> <p>--</p> <p>d</p> <p>--</p> <p>e</p> <p>--</p> <p>f -</p> <p>-</p>	<p>Retains many major facts re self.</p> <p>Knows own name.</p> <p>No assistance toileting or eating but may require assistance choosing proper attire.</p>
<p>6 a -</p> <p>-</p> <p>.</p> <p>b --</p> <p>c --</p> <p>d -</p> <p>-</p> <p>e --</p>	<p>Difficulty putting clothes on properly without assistance.</p> <p>Unable to bathe properly e.g. difficulty adjusting bath water temperature.</p> <p>Inability to handle mechanics of toileting e.g. forgets to flush; doesn't wipe properly.</p> <p>Urinary incontinence.</p> <p>Faecal incontinence.</p>
<p>7 a -</p> <p>-</p> <p>b -</p> <p>-</p> <p>c --</p> <p>d -</p> <p>-</p> <p>e --</p> <p>f --</p>	<p>Ability to speak limited to about half a dozen words in an average day.</p> <p>Intelligible vocabulary limited to a single word in an average day.</p> <p>Non ambulatory (unable to walk without assistance).</p> <p>Cannot sit up without assistance.</p> <p>Loss of ability to smile.</p> <p>Loss of ability to hold head up independently.</p>

COPE QUESTIONNAIRE

CARER DETAILS

YOUR DATE OF BIRTH: (day/month/year)

IN GENERAL WOULD YOU SAY YOUR HEALTH IS:

Very good Good Fair Poor Very poor

WHAT IS YOUR RELATIONSHIP TO THE PERSON YOU CARE FOR?

Spouse/Partner Sibling
Child Daughter or Son-in-law
Other Family Friend/Neighbour

YOUR GENDER:

Male Female

YOUR OCCUPATIONAL STATUS:

Employed full-time Employed part-time
Retired Unemployed
Full-time Study

WHERE DO YOU AND THE PERSON YOU CARE FOR LIVE?

In the same household
In different households but the same building
Within walking distance
Within 10 minutes drive/bus or train journey
Within 30 minutes drive/bus or train journey
Within 1hours drive/bus or train journey
Over 1hours drive/bus or train journey

COPE INDEX

Overall, do you feel well supported in your role of caregiver?

Always Often Sometimes Never

Do you feel you cope well as a caregiver?

Always Often Sometimes Never

Do you find caregiving too demanding?

Always Often Sometimes Never

Does caregiving cause difficulties in your relationships with friends?

Always Often Sometimes Never N/A

Does caregiving have a negative effect on your physical health?

Always Often Sometimes Never

Does caregiving cause difficulties in your relationship with your family?

Always Often Sometimes Never
N/A

Does caregiving cause you financial difficulties?

Always Often Sometimes Never

Do you feel trapped in your role as a caregiver?

Always Often Sometimes Never

Do you feel well supported by your friends and/or neighbours?

Always Often Sometimes Never
N/A

Do you find caregiving worthwhile?

Always Often Sometimes Never

Do you feel well supported by your family?

Always Often Sometimes Never
N/A

Do you have a good relationship with the person you care for?

Always Often Sometimes Never

Do you feel well supported by health and social services?
(for example, public, private, voluntary)

Always Often Sometimes Never N/A

Do you feel that anyone appreciates you as a caregiver?

Always Often Sometimes Never N/A

Does caregiving have a negative effect on your emotional well-being?

Is there anything else you would like to tell us?

Carer’s Assessment of Difficulties Index (CADI)

Below are some statements which carers have made about the difficulties they face. Please read each statement and show if it applies to you by circling the appropriate number in Column A.

For each statement which sometimes or always applies to you, please show how stressful you find it by circling the appropriate number in Column B.

Ratings

<p>Column A</p> <p>This statement</p> <p>Never applies to me - 1</p> <p>Sometimes applies to me - 2</p> <p>Always applies to me - 3</p>	<p>Column B</p> <p>I Find this aspect of caring</p> <p>Not stressful - 1</p> <p>Moderately stressful - 2</p> <p>Very stressful - 3</p>
--	---

	A	B
I don't have enough private time for myself.		
I sometimes feel helpless/not in control of the situation.		
I can't devote enough time to other family members.		
It causes financial difficulties.		

The person I care for sometimes manipulates me.		
The person I care for is immobile/has problems in getting around.		
Professional workers don't seem to appreciate the problems carers face.		
It restricts your social life/outside interest.		
It can put a strain on family relationships.		
It is physically tiring.		
The person I care for can demand too much of me.		
I no longer have a meaningful relationship with the person I care for.		
The person I care for needs a lot of help with personal care.		
The person I care for doesn't always help as much as they could.		

My sleep is affected.		
Relatives don't keep in touch as often as I'd like.		
I feel angry about the situation.		
I can't see friends as often as I'd like.		
My emotional well-being suffers.		
I can't have a break or take a holiday.		
My standard of living has fallen.		
The person I care for doesn't always appreciate what I do.		
My physical health has suffered.		
The person I care for is incontinent.		
The behaviour of the person I care for is a problem.		

There is no satisfaction to be gained from caring.		
I don't get enough help from the health and social services.		
Some family members don't help as much as they could.		
I can't relax because of worry about caring.		
I feel guilty about the situation.		

Satisfaction with End of Life Care in Dementia Questionnaire (SWC-EOLD)

Can you please place a tick in the box to indicate which one of the following four categories applies to the question:

Questions	Strongly disagree	Disagree	Agree	Strongly agree
I felt fully involved in all decision making				
I would probably have made different decisions if I had had more information				
All measures were taken to keep my relative comfortable				
The health care team was sensitive to my needs and feelings				
I did not really understand my relatives condition				
I always knew which doctor or nurse was in charge of my relatives				

care				
I feel that my relative got all necessary nursing assistance				
I felt that all medication issues were clearly explained to me				
My relative received all treatments or interventions that he or she could have benefited from				
I feel that my relative needed better medical care at the end of his or her life				

We appreciate that this is a difficult time for yourself and your family. If there are issues regarding the care and support that your loved one or yourself received and you would like to discuss these, and/or you would like bereavement advice/support, please do not hesitate to contact the project nurse specialist Sharon Scott on 0208 776 5656.

Thank you for completing this questionnaire. We hope it will enable us to further develop the care and support that people with advanced dementia and their carers' need towards the end of life.

Name of person completing questionnaire :.....(You do not have to give your name)