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An evaluation of the role of the Admiral Nurse: a systematic evidence synthesis to inform service delivery and research

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Background

Two thirds of people with dementia live in the community and receive support from family members. There is a great deal of evidence to suggest that caring for a person with dementia impacts on the health and wellbeing of family carers. Despite this the provision of funded support for family carers is often limited or inadequate. Admiral Nurses, developed in the 1990s, were specifically designed by the charity *for dementia* (now Dementia UK) to support the family carers of people with dementia. Admiral Nurses are mental health nurses specialising in the care of people with dementia. They are mainly employed by local providers of care for people with dementia but dementia UK is involved in setting up new posts and providing ongoing practice development. There are currently around 100 Admiral Nurses employed in England. In addition the charity has a national helpline provided by experienced Admiral Nurses. The evidence synthesis presented here was commissioned by Dementia UK in order to establish what is currently known about the scope, nature and effectiveness of Admiral Nurses.

Aims & objectives

The overall aims of the project were to: 1) synthesise the literature on the scope and effectiveness of Admiral Nurses, 2) set the evidence on Admiral Nurses in the context of other community-based initiatives to support people with dementia and their family carers and, 3) provide a baseline to inform future research on the role and effectiveness of Admiral Nurses.

Methods

The evidence synthesis was conducted systematically in two phases addressing the objectives of the project:

1) A scoping of literature relating to the role of the Admiral Nurse and,

2) A review of reviews evaluating community based dementia support

Literature selection criteria

Phase 1 included all types of literature that related to the scope and effectiveness of Admiral Nurses; including empirical research, descriptive reports and published and unpublished literature. Phase 2 included systematic reviews that either evaluated the role of community based dementia support

workers or evaluated community based interventions designed to support the carers of people with dementia. Phase 1 only included studies relating to Admiral Nurses but phase 2 included interventions delivered by any provider including non-nurses.

Data sources

We searched the following electronic databases: Medline (PubMed), CINAHL, Scopus, NHS Evidence, Cochrane Library (incl. CENTRAL, CDSR, DARE, HTA), SIGLE and Google Scholar. In addition we used lateral searching techniques such as checking reference lists, using the 'cited by' option in Google Scholar and Scopus and the 'related articles' option on PubMed, and contacting experts in the field. Searches were conducted in November 2012.

Data extraction, quality assessment and synthesis

Two reviewers independently screened electronic records, extracted data and assessed study quality using specially designed checklists. In phase 1 we extracted data relating to the scope and key attributes of the role of Admiral Nurses, who they work with, and outcomes and impact arising from their work. In addition we used qualitative analysis techniques to draw out common themes. In phase 2 we extracted data relating to the format of the intervention and the impact on carers and people with dementia (e.g. satisfaction, physical and mental wellbeing and service use).

Main results

Phase 1

After full text review 36 items met the inclusion criteria for phase 1. Of these ten were classified as research and the rest as non-research (e.g. service announcements, descriptive items in professional journals and news reports). We found no published evidence related to the Admiral Nurse telephone helpline (Admiral Nurse DIRECT) although Dementia UK are currently undertaking an evaluation of this service. The following therefore relates to those Admiral Nurses working in locally organised teams.

The evidence base relating to Admiral Nurses is currently limited but the following findings emerged.

The Admiral Nurse role: scope, nature and attributes

- There is a consensus in the literature that core components of the Admiral Nurse role include the provision of emotional, psychosocial and educational support to family carers of people with dementia through individual case work.
- Key attributes that characterise the Admiral Nurse role are a focus on the family carer as the client, and the ability to assess carer needs, provide therapeutic interventions for carers, develop a therapeutic relationship and offer information, skills training and education.
- Admiral Nurses are reported by carers as important sources of information, providing information about dementia, the diagnosis process, responding to and coping with changing behaviour associated with dementia and the impacts that dementia has on the person and the family.
- Admiral Nurses act as consultants to other health care professionals although it is not clear how they balance their consultancy and case work roles.
- The role of the Admiral Nurse appears to be influenced by local contextual factors, such as inadequacies in statutory services.
- Admiral Nurses have traditionally worked in small teams based in local mental health and social care services and have covered wide geographical areas. More recently they have diversified into different settings including care homes and primary care.
- There is evidence to suggest that admiral nurses may find it difficult to refuse new cases and increasing workloads may impact on the ability of the service to provide on-going support.

Recurrent themes in the literature

Three overarching thematic categories were identified as being central to the role and impact of Admiral Nurses:

- Relational support, including the subthemes of carer-centred approach, individually tailored, and Admiral Nurse as friend.
- Co-ordinating and personalising support, including the subthemes of facilitation, collaboration, and advocacy.
- Challenges and threats to the provision of services by Admiral Nurses; including the subthemes of caseloads, providing care across the dementia trajectory, defining the role, and relationship dynamics.

Evidence of effectiveness and impact

- There is evidence to suggest carers are satisfied with Admiral Nurses and value the emotional support and education provided.
- There appears to be a good fit between evidence relating to what carers of people with dementia want from services and the role of the Admiral Nurse.
- Much of the available literature is descriptive and there has been little work to evaluate specific interventions provided by Admiral Nurses.
- The literature on Admiral Nurses is characterised by the challenges that have faced evaluations of other similar nursing roles. Limitations in methodology make it difficult to make definitive statements about effectiveness and measurable outcomes.

Phase 2

In phase 2 we looked to establish the evidence for activities that might support carers of people with dementia and to map this against the literature relating to the support provided by Admiral Nurses. We found 13 previously published systematic reviews evaluating a range of community based support, some of the key findings are:

- Interventions reviewed included case management, psychosocial interventions and education. The most commonly reported outcomes were levels of caregiver depression and burden, and rates of admission to hospital and nursing homes for people with dementia.
- There is a considerable amount of evidence relating to community based interventions to support people with dementia and their family carers but evidence relating to the effectiveness of these interventions is mixed.
- In general the evidence that interventions reduced caregiver depression or burden was weak although there was some evidence that psychosocial and educational interventions reduced depression in carers.
- There was some evidence that case management, psychosocial and educational interventions could reduce or delay admission to nursing home of the person with dementia but little evidence they reduced hospital admissions or resource use.
- Most reviews did not specify if, or in what way, nurses were involved in the interventions but many of the interventions (e.g. case management, psychosocial interventions and education) are within the remit of Admiral Nurses.

Conclusions

Our review synthesises current evidence about the scope and effectiveness of Admiral Nurses, and the evidence around community based support for people with dementia and their family carers. We also highlight some of the challenges that face Admiral Nurses.

Policy and practice implications

Based on our findings, we offer the following recommendations for policy and practice.

- Descriptive and qualitative evidence suggests that Admiral Nurses are valued by family carers but the impact of their work is not so clearly established. There is a need to define outcomes that can help organise the service and inform future service delivery.
- Increasing caseloads and the wide range of demands on Admiral Nurses may impact on the service they can provide and there is a need for realistic, and common, goals about what the service can and can't achieve.
- There are relatively small numbers of Admiral Nurses covering large geographical areas and there is evidence that services may be overstretched. There may be a need to reconsider the way the service works with other services and for which groups and at what stage in the dementia trajectory efforts should be focused. There is currently little evidence relating to optimal caseloads or frequency of contact.
- The Admiral Nurse role has common attributes and areas of practice however the absence of clearly articulated goals and shared objectives means that how the service is delivered is subject to the geographical location of the service and the needs of the host organisation and local area.

Implications for research

- The literature reviewed suggests that context, the needs of the host organisation, and practitioner experience and focus have shaped how the role is delivered in different settings. Future research should consider what the Admiral Nurse role should achieve at different stages of the dementia trajectory and what outcomes are meaningful at service and individual levels of care. Research designs that draw on realist methodologies of what works when and with what outcomes may offer more scope for judging effectiveness

- There appeared to be a good fit between evidence relating to what carers of people with dementia want from services and the role of the Admiral Nurse. However, there has been little work undertaken to evaluate the specific interventions Admiral Nurses provide.
- Although there was some evidence to suggest that the scope of influence of Admiral Nurses extended into other settings beyond working with people in the community (e.g. working with acute hospitals and care homes) there are no formal evaluations of these services.
- There is a lack of information of how Admiral Nurses' work with other services e.g. GPs, Community Mental Health Services. There is a need to investigate the contribution of Admiral Nurses from the perspective of other stakeholders such as statutory and voluntary service providers and commissioners.
- Although consultancy and education of other health care professionals appears to be a part of the Admiral Nurse role this is not well described in the literature. Further work is needed to establish the scope and impact of this aspect of their role.
- Current literature provides limited information about the needs of clients that Admiral Nurses work with. Further work may be needed to look at the profile of carers that Admiral Nurses support and to understand what aspects of carers' needs the service addresses.
- There are well documented methodological problems associated with evaluating complex interventions in the context of people who have deteriorating conditions. Future evaluations should take these into consideration.

1. Introduction

Dementia affects one in 20 people over the age of 65 and one in five over the age of 80 (ADI 2009). Over 800,000 people in the United Kingdom have dementia (Luengo-Fernandez et al., 2010), the most common form being Alzheimer's disease (Alzheimer's, 2007). This number will double to 1.4 million in the next 30 years (Alzheimer's Society, 2007) with an estimated cost of £40 billion (Kings Fund, 2008). Although there are significant differences in the physical and cognitive effects of the different types of dementias all are progressive, involve increasing physical and mental deterioration, and lead to a sufferer becoming increasingly dependent.

Around two thirds of people with dementia live in the community (National Audit, 2007) with about 70% receiving care from family members. Estimates of the current number of family/unpaid carers of people with dementia in the UK range from 476,000 to 670,000 (National Audit, 2007, Alzheimer's Research Trust, 2010). As the population ages, and the number of people with dementia rises, there will be an accompanying increase in the number of family carers looking after people with dementia, many of whom have multiple health and social care needs (Hofman et al., 1991). It is well documented that caring for a person with dementia impacts on the health (physical and mental) and wellbeing of family carers (Bunn et al., 2012, Ory et al., 1999, Connell C.M. et al., 2001). In a meta-analysis comparing the physical and psychological health of carers and non-carers, carers were found to have higher levels of depression and stress and reduced self-efficacy and subjective well-being than non-carers (Pinquart and Sarensen, 2003). Dementia caregivers also spend significantly more hours per week providing care then non dementia caregivers and there are greater impacts in terms of employment complications and family conflicts (Ory et al., 1999).

Despite the well-documented physical, psychological, practical and economic impact of caring for a family member with dementia there is evidence to suggest that the provision of support for carers is often inadequate (Bunn et al., 2012, Georges et al., 2008). A recent thematic analysis of over 100 qualitative studies of patient and carer experiences of dementia diagnosis and treatment (Bunn et al., 2012) found that, although recent years had seen improvements in access to specialist diagnostic services, post-diagnosis support was still frequently considered inadequate by family carers. It is clear, that there is a need to provide greater support for people caring for a family member with dementia. However, it is not clear which interventions are most effective in reducing carer stress, improving their quality of life and helping them to continue in their caring role.

Admiral Nurses are mental health nurses who specialise in supporting family carers of people with dementia. The concept was first piloted in Westminster in 1990 and named in memory of Joseph

Levy CBE BEM, who had vascular dementia and was known as 'Admiral Joe' by his family and friends. The charity Dementia UK was established to take forward the concept of Admiral Nurses. The charity works closely with statutory NHS mental health and social care services that have Admiral Nurses based in their services. More latterly the charity has worked with other types of organisations such as a not for profit hospice charity, the Royal British Legion, and care home providers who have decided to employ Admiral Nurses. The Charity introduced a national helpline staffed by experienced Admiral Nurses in 2008. The charity provides a network of support and training for Admiral Nurses. There are currently around 100 Admiral Nurses employed in England and Wales (as of the end of 2012) Initially all Admiral Nurses worked within Admiral Nurse teams but more recently the model has diversified and Admiral Nurses are now based in a variety of settings including care homes and primary care. The aim of the Admiral Nurse intervention is to focus on meeting the needs and improve the quality of life of carers and families of people with dementia (http://www.dementiauk.org/what-we-do/mission-statement-objectives/).

Specialist nurses have been introduced to improve service quality and co-ordinate care for people with a number of long term conditions such as multiple sclerosis (Forbes et al., 2003), cancer (Cruickshank et al., 2008) and Parkinson's disease (Reynolds et al., 2000). However, whilst there is a large body of work on the role of specialist nurses in the management of long-term conditions (Trivedi et al., 2009) relatively little is known about the effectiveness of specialist nurses for people with dementia and more specifically their family carers (Griffiths et al., 2013). This report is based on an evidence synthesis commissioned by Dementia UK in order to establish what is currently known about the scope, nature and effectiveness of Admiral Nurses.

2. Aims

The overall aims of the project were to: 1) synthesise the literature on the scope and effectiveness of Admiral Nurses, 2) situate the evidence on Admiral nurses in the context of other community-based initiatives to support people with dementia and their family carers and 3) provide a baseline to inform future research on the role and effectiveness of Admiral nurses.

The research questions were:

1. What is the scope and nature of the Admiral Nurse role?
2. What are the key attributes of Admiral Nurses?
3. Who do Admiral Nurses work with and how are they embedded in health and social care systems?

4. What are the recurrent themes and issues relating to how Admiral Nurses support family carers and people with dementia?
5. What does current evidence tell us about the effectiveness of Admiral Nurses?
6. How does the contribution of Admiral Nurses compare to other community based dementia specific roles (e.g. in the international literature)?
7. What are the gaps in the evidence and areas for future research?

3. Methods

The evidence synthesis was undertaken in two phases:

1) A scoping of literature relating to the role of the Admiral Nurse and,

2) A review of reviews evaluating community based dementia support

3.1. Phase 1: Scoping of the literature on Admiral Nurses

The scoping was guided by Arksey and O'Malley's methodological framework (Arksey and O'Malley, 2005, Levac et al., 2010). This includes: identifying the research question, searching for relevant studies, selecting studies, charting the data, collating, summarizing and reporting the results.

3.1.1. Identifying the research question

We were guided by our pre-specified research questions and included all types of literature that related to the scope and effectiveness of Admiral Nurses in the UK. This encompassed empirical research and descriptive reports, and both published and unpublished literature. As phase 1 looked specifically at the role of Admiral Nurses any literature referring to other types of dementia specialist workers were excluded at this stage.

3.1.2. Searching for relevant studies

Our search strategy was designed to be broad and sensitive enough to ensure we captured all potentially relevant literature. It included highly sensitive electronic search strategies and the employment of lateral searching techniques. Searches included:

- Electronic databases including: Medline (PubMed), CINAHL, Scopus, NHS Evidence, Cochrane Library (incl. CENTRAL, CDSR, DARE, HTA), SIGLE, Google Scholar.

- Checking of reference lists from primary studies and systematic reviews (snowballing) (Dixon-Woods, 2006)
- Citation searches using the 'Cited by' option on WoS, Google Scholar and Scopus, and the 'Related articles' option on PubMed and WoS ('Lateral Searching') (Greenhalgh and Peacock, 2005)
- Contact with experts and those with an interest in dementia to uncover grey literature (e.g. Dementia UK, DeNDRoN, National Library for Health Later Life Specialist Library, E alerts through dementia specific networks (e.g. Alzheimers RCN BGS)

Searches were conducted in November 2012. Full search terms can be seen in Appendix 1.

3.1.3 Selecting studies and charting the data

Electronic search results were downloaded into EndNote bibliographic software and, where possible, duplicates deleted. As there is evidence that two reviewers should screen records to maximize ascertainment of relevant studies (Edwards et al., 2002) two reviewers independently screened titles and abstracts against the above predefined inclusion criteria. Full manuscripts of all potentially relevant citations were screened independently by two reviewers using a screening form with the clearly defined criteria. Any disagreements were resolved by consensus or by discussion with a third author.

Papers were categorised as research or non-research. Research papers were further categorised by study design (e.g. controlled evaluation, qualitative study, questionnaire), and non-research papers were categorised as policy documents, publications for professionals, news reports or service announcements. Where the results of a study were reported in more than one publication we grouped reports together and marked the publication with the most complete data as the primary reference; the other papers describing the same study were classified as associated papers. Data extracted varied according to the type of material. Data from empirical studies included: study type, aims/research questions, study methods, types of participants, setting and relevant outcome data (such as information on effectiveness or patient experiences). For grey literature and reports data included: type of item (e.g. policy document, guideline, description of role, service announcement), a summary and description of service development and outcome data.

Two reviewers independently assessed the quality of the research studies using design assessment checklists. The quality criteria were informed by several sources (Higgins et al., 2011, Spencer et al., 2003, Shea et al., 2007, CEBMa). The checklist for qualitative studies was an adapted version of the framework for assessing quality in qualitative research designed by Spencer and colleagues (Spencer

et al., 2003), and had been used by the authors in previous work (Bunn et al., 2008, Pocock et al., 2010). In addition to the checklist the overall reliability and usefulness of the study to the research questions was graded as low, medium or high. Any discrepancies were resolved by discussion. The core quality-assessment principles are summarised in Appendix 2.

3.1.4 Reporting the results

Data are presented as a narrative and tabular summary. Results include a description of the scope and key attributes of the role of Admiral Nurses, who they work with, and outcomes and impact arising from their work. In addition, qualitative analysis techniques were used to draw out common themes. All qualitative papers, or papers that provide qualitative or descriptive data, were read and coded by one author and codes and potential themes were identified. Themes were checked and verified by a second author who also independently read and coded 50% of the studies. Codes were refined after discussion and grouped into overarching themes and subthemes. The thematic analysis was informed by theories of continuity of care (Fulop and Allen, 2000, Parker et al., 2009), which refers to relationships between patients and practitioners, coordination across services, information transfer and coordination of care over time, and the coherent delivery of services for people with long term conditions (Haggerty et al., 2003).

3.2. A review of community based dementia support

The second phase of the synthesis involved an evaluation of the effectiveness of community based support for people with dementia and their carers. This enabled us to compare what is known about the effectiveness of community based support for people with dementia and their carers' with what is known about the scope and practice of Admiral Nurses.

3.2.1 Inclusion criteria

Types of studies

Phase 2 was conducted as a review of previously published reviews. This was because the review needed to be conducted rapidly and preliminary searches had identified that there were already a number of systematic reviews in this area.

Types of intervention

We included systematic reviews that either a) evaluated the role of community based dementia support workers or b) evaluated community based interventions designed to support the carers of

people with dementia. This could include interventions delivered by both nurses and non-nurses. Components of community support might include one or more of the following: assessment, the provision of information and advice, emotional and psychological support, practical support, and collaboration with other professionals and organisations in order to co-ordinate care provision.

Types of participants

Participants included people with dementia, and their family carers, who were living in their own homes in the community. Reviews that focused on residential or secondary care settings were excluded.

Types of outcomes

We included any outcome relating to the following:

- Carer and patient satisfaction
- Physical and mental wellbeing of the carer or person with dementia
- Service use (e.g. admission to nursing home or hospital for the person with dementia)

3.2.2. Identification of studies

The databases searched and lateral search strategies used were the same as those for stage one of the synthesis (described above in 3.1.2). Search terms can be seen in Appendix 1.

3.2.3. Data extraction and critical appraisal

Data extracted included: (1) review quality (2) aims/research question: (3) type of intervention: (4) methods of analysis: (5) type of participants (including age, sex, ethnicity): and (6) outcomes. Two reviewers independently appraised the quality of the reviews using AMSTAR a tool designed to assess the methodological quality of systematic reviews (Shea et al 2007). This tool includes 11 items and covers aspects of review quality such as evidence of 'a priori' design, and procedures for study selection, data extraction, critical appraisal, analysis and reporting.

3.2.4: Analysis and presentation of results

Interventions were classified using the following categories:

- Psychosocial support

- Education
- Case management
- Multi-component interventions
- Other (included miscellaneous interventions such as respite)

Results are presented in the text by outcome and by type of intervention.

4. Overview of literature included in the synthesis

The electronic search yielded 4455 items from all databases, reduced to 3533 after duplicates were removed. Of these 174 appeared potentially relevant and a hard copy was obtained for screening. After full text review 36 items met the inclusion criteria for phase one of the review and 13 reviews met the criteria for phase two. An overview of the selection process can be seen in Figure 1 and a full list of the included literature can be seen in Appendix 3.

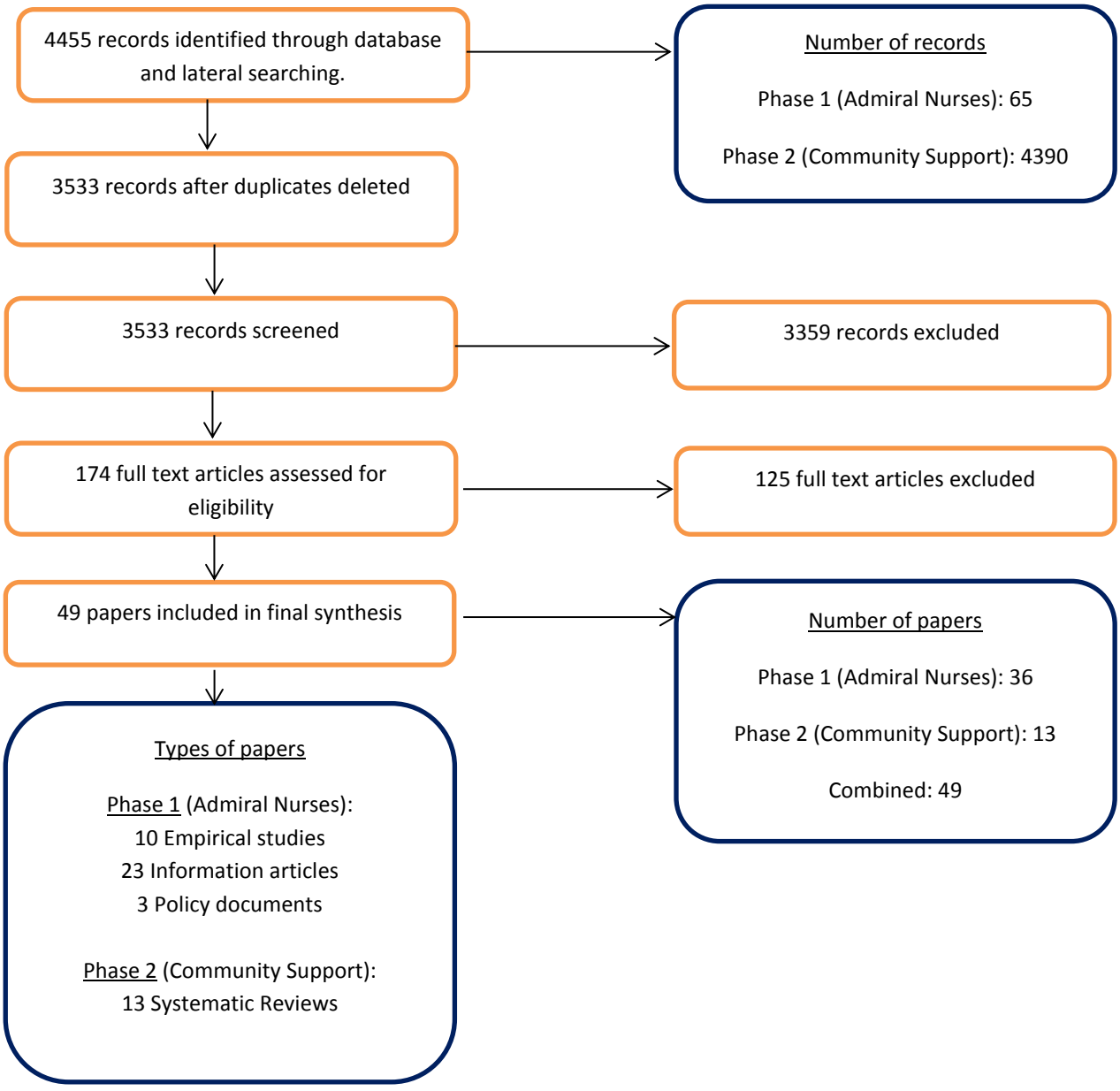

Figure 1: Flow Chart of Study Selection

4.1 Description of studies

4.1.1 Phase 1

Of the 36 items included in phase 1 ten were classified as research, one of which was an audit (Stamper & Taylor, 2011), and the rest as non-research. Of the ten research items five are published in peer review journals (Burton & Hope, 2005; Dewing & Traynor, 2005; Keady et al, 2007; Quinn et al 2012; Woods et al, 2003), one is a published report available on the Dementia UK website (Clare et al, 2005), one is an unpublished PhD doctorate (Hibberd, 2011) and the other three are unpublished reports obtained from Dementia UK (Stamper & Taylor, 2011; Woods & Algar, 2009; Maio, 2011). Of the remaining items three are policy documents that include a specific mention of Admiral Nurses and 23 are non-research items. These non-research items were further sub-divided into service announcements (n=3), publications for professionals such as the Nursing Standard (n=11) and descriptive items such as news reports (n=9). Further details of all included items can be seen Appendix 4, and the publication year and type of literature can be seen in Figure 2. The included items are published between 1995 and 2012 but the first research study was not published until 2001.

The methodology of the research studies varied. Three are qualitative studies (Burton & Hope, 2005; Keady et al, 2007; Quinn et al, 2012), one is a controlled study (Woods et al, 2003), four used a mixed methodology comprising both qualitative and quantitative methods (Clare et al, 2005; Hibberd, 2011; Maio, 2011; Woods & Algar, 2009), one is an audit of existing services (Stamper & Taylor, 2011) and one is an action research project (Dewing & Traynor, 2005). The study that utilised the greatest variety of methods was a PhD (Hibberd, 2011) which included a survey, telephone interviews, photography, narratives, questionnaires and focus groups. The results from that study are also reported in an associated paper; Hibberd et al (2009), which reports on the use of photographs and narratives to explore the changing nature of carer and person with dementia's relationship.

The controlled study (Woods et al, 2003) compared results of the General Health Questionnaire for carers receiving support from an Admiral Nurse with those receiving other specialist community services but not Admiral Nurses. Four studies evaluated the AN service via the use of questionnaire surveys looking at carer satisfaction and carers experiences of the service (Stamper & Taylor, 2011; Clare et al, 2005; Maio, 2011Woods & Algar, 2009), four used interviews (Burton & Hope, 2005; Keady et al, 2007; Quinn et al, 2012; Woods & Algar 2009), and one used a series of meetings with Admiral nurses as part of an action research approach (Dewing & Traynor, 2005).

1995	Butterworth *(Non-research)* Greenwood & Walsh *(Non-research)* Woods *(Non-research)*
1998	Meredith *(Non-research)*
2000	Armstrong *(Non-research)*
2002	Pinto-Banerji *(Non-research)*
2003	Soliman *(Non-research)* Woods et al *(Research)*
2005	Burton & Hope (*Research*) Clare et al (*Research*) Dewing & Traynor (*Research)* Keady *(Non-research)*
2006	Heath *(Non-research)*
2007	Braker *(Non-research)* Keady et al (*Research)* Thompson & Devenney *(Non-research)*
2008	Armstrong *(Non-research)* Hibberd, Lemmer et al *(Non-research)* Jackson *(Non-research)* Sarna & Thompson *(Non-research)* Weatherhead*(Non-research)*
2009	Ghiotti*(Non-research)* Hibberd et al *(Research)* Kendall-Raynor*(Non-research)* Weatherhead*(Non-research)* Woods & Algar *(Research)*
2010	Kendall-Raynor *(Non-research)*
2011	Hibberd *(Research)* Hibberd*(Non-research)* Maio *(Research)* Stamper & Taylor (*Research)*
2012	Quinn et al *(Research*) Williams *(Non-research)*

Figure 2: Timeline of included Literature

Several studies explored aspects of the relationship dynamics between the Admiral Nurse, the carer and the person with dementia. For example, Hibberd (2011) looked at the impact of dementia on the relationship between the carer and the person with dementia, and Quinn et al (2012) explored the triadic relationship between spousal caregivers, people with dementia and Admiral Nurses. One paper looked at the role and attributes of an Admiral Nurse, and the factors considered by the Admiral Nurse Service at the point of referral (Burton & Hope, 2005) and one concerned the development of a competency framework for Admiral Nurses (Dewing & Traynor, 2005).

Of the twenty three non-research items, thirteen were focused on the role of the Admiral Nurse, six discussed projects involving an Admiral Nurse and the rest explore issues such as access to Admiral Nurses for black and minority ethnic groups, the use of a family centred approach to dementia care, the feasibility of a specialist community nurse for people with dementia living at home, and an announcement that an Admiral Nurse has been appointed in a care home. Twelve of the non-research items were written by an Admiral Nurse and these describe aspects of their role and the organisations in which they operate.

The three policy documents included in the review made reference to the Admiral Nursing service but little information was provided (DH, 2006; Health Foundation, 2011; RCN, 2010). One (Health Foundation 2011) mentions post diagnostic support groups run by Admiral Nurses, one (RCN 2010) gives an explanatory statement about the day to day work of an Admiral Nurse alongside similar information about other specialist nursing roles and one (DH 2006) provides a basic example of the role of the Admiral Nurses.

4.1.2 Phase 2

We found thirteen systematic reviews evaluating community based interventions to support people with dementia and their carers. Three reviews had pooled studies in a meta-analysis (Pinquart & Sorenson, 2006; Tam-Tham et al, 2012; Thompson et al 2007) and the remainder presented their findings in a narrative format (Brodaty et al, 2003; Cooke et al, 2001; Hall & Skelton, 2012; Parker et al, 2008; Peacock & Forbes, 2003; Pimouguet et al, 2010; Pusey & Richards, 2001; Schoenmakers et al, 2010; Smits et al, 2007; Somme et al, 2012). The reviews included interventions delivered to both carers and people with dementia. One review focused primarily on interventions for the person with dementia but also provided some data on outcomes for carers. (Somme et al, 2012), two reviews explored interventions for both the carer and the person with dementia (Schoenmakers et al, 2010; Smits et al, 2007), and one (Pimouguet et al 2010) evaluated the cost effectiveness of case

management. The remaining eight focused on interventions aimed at the carer. Further details of the included reviews can be seen in Appendix 5.

The reviews evaluated a range of interventions, and many had a broad scope which encompassed a number of different types of interventions within the same review. We classified interventions as: case management, psychosocial, educational, multi-component and "other". Case management was evaluated in five reviews (Peacock & Forbes, 2003; Pimouguet et al, 2010; Schoenmakers et al, 2010; Somme et al, 2012; Tam-Tham et al. 2012), two of which (Peacock & Forbes 2003; Schoenmakers et al 2010) explored the impact of case management in combination with other interventions; psychosocial interventions were explored in six reviews (Brodaty, 2003; Cooke et al, 2001; Pusey & Richards, 2001; Schoenmakers et al, 2010, Parker et al, 2008; Pinquart & Sorenson, 2006); interventions based on education in three (Parker et al 2008, Peacock & Forbes 2003 Pinquart & Sorenson 2006); and multi-component interventions in three (Parker et al 2008, Pinquart & Sorenson 2006; Smits et al 2007). Within the "other interventions" category are studies on; respite (Pinquart & Sorenson, 2006; Schoenmakers et al, 2010) and communication (Schoenmakers et al, 2010).

Only one review (Hall & Skelton 2012) compared interventions delivered by different groups of health care professionals. They explored the contribution of different professional groups including occupational therapists, nurses and multidisciplinary teams. In general the included reviews provided little information about who delivered the intervention and the contribution of nurses was not clear.

4.2 Quality of the evidence

4.2.1 Phase 1

A summary of the quality appraisal results for the research papers/reports can be seen in Table 1. Of the studies assessed using the qualitative checklist two study scored "high" for reliability (Keady et al, 2007; Quinn et al, 2012) two scored "medium" (Burton & Hope, 2005; Hibberd, 2011) and one (Dewing & Traynor 2005) scored "low". However, the latter was an action research project and our quality assessment framework may not have been appropriate for this type of study. When rated using the usefulness category, four of the studies scored highly (Dewing & Traynor, 2005; Hibberd, 2011; Keady et al, 2007; Quinn et al, 2012) and one scored "medium" (Burton & Hope, 2005). The controlled evaluation was judged to be at high risk of bias (Woods et al, 2003). The three mixed methods studies that involved questionnaire surveys all fulfilled five out of the eight categories on

which they were judged (Clare et al, 2005; Woods & Algar, 2009, Maio 2011). The original samples sizes in the questionnaires surveys were 62 (Woods & Algar 2009), 82 (Maio 2011), and 1607 (Clare et al 2005) but response rates were similar at 36%, 37.5% and 33% respectively. These low response rates suggest that the findings may not be generalisable to all users of the service. Furthermore, responses in one survey (Woods & Algar 2009) largely relate to only one nurse which raises further doubts about generalisability.

Table 1: Overview of quality assessment Phase 1

Reference	Type of study	Quality assessment tool used	Quality assessment rating
Burton & Hope (2005)	Qualitative	Spencer and Ritchie (2003)	Reliability: Medium Usefulness: Medium
Clare et al (2005)	Mixed (questionnaire)	CEBMa Critical Appraisals of a Survey	Yes: 5/8
Dewing & Traynor (2005)	Qualitative	Spencer and Ritchie (2003)	Reliability: Low Usefulness: High
Keady et al (2007)	Qualitative	Spencer and Ritchie (2003)	Reliability: High Usefulness: High
Hibberd (2011)	Qualitative	Spencer and Ritchie (2003)	Reliability: Medium Usefulness: High
Maio (2011)	Mixed (questionnaire)	CEBMA Critical Appraisals of a Survey	Yes: 5/8
Quinn et al (2012)	Qualitative	Spencer and Ritchie (2003)	Reliability: High Usefulness: High
Woods et al (2003)	Quantitative	Cochrane Risk of Bias Tool	High risk of bias
Woods & Algar (2009)	Mixed (questionnaire)	CEBMa Critical Appraisals of a Survey	Yes: 5/8

4.2.2 Phase 2

A summary of the quality assessment scores for the systematic reviews can be seen in Table 2. Tam-Tham et al (2012) was the only review to meet all 11 of the quality criteria. The reviews fulfilling the lowest number of criteria are Pimouguet et al (2010), Pinquart & Sorenson (2006) and Somme et al (2012), which all met only five out of the 11 criteria. Pinquart & Sorenson pooled findings in a meta-analysis but interpretation of their findings is difficult as they provide no information about how many studies had been included in each category.

Table 2: Overview of review quality

Reference	Total number of fulfilled criteria	Total number of unfulfilled criteria	Total number of criteria marked 'unsure'
Brodaty et al (2003)	6**/11**	3**/11**	2**/11**
Cooke et al (2001)	6**/11**	3**/11**	2**/11**
Hall & Skelton (2012)	7**/11**	2**/11**	2**/11**
Parker et al (2008)	9**/11**	2**/11**	0**/11**
Peacock & Forbes (2003)	7**/11**	2**/11**	2**/11**
Pimouguet et al (2010)	5**/11**	4**/11**	2**/11**
Pinquart & Sorenson (2006)	5**/11**	3**/11**	3**/11**
Pusey & Richards (2001)	8**/11**	2**/11**	1**/11**
Schoenmakers et al (2010)	8**/11**	1**/11**	2**/11**
Smits et al (2007)	6**/11**	2**/11**	3**/11**
Somme et al (2012)	5**/11**	4**/11**	2**/11**
Tam-Tham et al (2012)	11**/11**	0**/11**	0**/11**
Thompson et al (2007)	9**/11**	1**/11**	1**/11**

5. Findings

5.1 The Admiral Nurse role: scope, nature and key attributes

Admiral Nurses are mental health nurses who specialise in supporting family carers of people with dementia. As of the end of 2012, there were about 100 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, but the charity Dementia UK provides a central organisational structure to support their work. Dementia UK also supports a telephone help line run by Admiral Nurses. Dementia UK (http://www.dementiauk.org) suggests that Admiral Nurse should:

- Offer a skilled assessment of the needs of the family carers and people with dementia.
- Provide information and practical advice for family carers on different aspects of caring for a friend/relative with dementia.
- Work with families at the point of diagnosis and throughout the caring journey, providing emotional and psychological support and guidance about accessing services.
- Help family carers and people with dementia to develop and improve skills to assist with care-giving and to promote positive approaches to living with dementia.
- Work collaboratively with other professionals and organisations to facilitate co-ordinated care provision.
- Work with family carers to enable them to express their wishes and views about the services they receive

Hibberd (2011b) writes that the approach of the Admiral Nursing service is underpinned by the stress-burden model (Zarit et al., 1985, Zarit and Zarit, 1982). This model looks at the impact of the availability of social support, symptoms of dementia (and the carers response to them) and the quality of the prior relationship of the carer and the person with dementia on the degree of burden experienced by carers. In their management model Zarit and colleagues describe the importance of providing information, problem solving, managing problem behaviour and increasing social support. Other more recent influences on the Admiral Nursing service include models of person-centred and relationship-centred care (Kitwood 1997, Clarke 1999, Keady et al 2007).

Competency framework

One study (Dewing and Traynor, 2005) described the use of action research methodology to facilitate the development of a competency framework that reflected the needs of the Admiral Nurses. The final framework includes the following eight core competencies:

- Therapeutic work (interventions)
- Sharing information about dementia & carer issues
- Advanced assessment skills
- Prioritizing work load
- Preventative and health promotion
- Ethical and person centred care
- Balancing the needs of the carer and the person with dementia
- Promoting best practice

Although this framework is also referred to in an evaluation of the East Kent Admiral Nursing Service (Stamper and Taylor, 2011) in general it was not clear from the literature to what extent these competencies have been universally adopted by Admiral Nurses or how they were used in the day to day work of Admiral Nurses.

Support provided by Admiral Nurses

From the literature it appeared that a key part of the Admiral Nurse role involves the provision of emotional and psychosocial support to the family carers of people with dementia. Admiral Nurses gave examples of this work which included: helping carers deal with negative emotions and the daily stresses of caring for someone with dementia (Clare et al., 2005), encouraging them to develop a support network (Meredith 1998), preventing them becoming overwhelmed by the carer role (Hibberd, 2011b), and promoting the development of methods to deal with negative changes in the behaviour of the person with dementia (Burton & Hope 2005). Several studies highlighted the fact that support was often provided long-term (Greenwood & Walsh 1995), continuing throughout the stages of dementia, including the transition of the person with dementia into care homes (Burton & Hope, 2005) and beyond (Keady et al 2007, Soliman 2003).

Admiral Nurses were reported to be important sources of information, providing information about dementia, the diagnosis process, responding to changing behaviour associated with dementia and the impacts that dementia has on the person and the family (Armstrong 2001, Burton & Hope, 2005,

Claire and Willis 2005, Maio 2011, Woods & Algar 2009). They were also reported to be involved in practical support, such as helping carers obtain benefits, and access services such as respite (Burton & Hope, 2005) and day hospitals (Clare et al, 2005). In addition there was a description of Admiral Nurses being involved in meeting the social needs of both the person with dementia and the carer through organising and running support groups (Weatherhead 2008, Meredith 1998, Braker 2007). Although one study reported that Admiral Nurses measured the blood pressure of the person with dementia and their carers (Woods & Algar, 2009) in general they did not appear to be involved in delivering "hands-on" physical or technical care.

There was evidence that some Admiral Nurses had a consultancy or educative role with other professionals. In the literature there were examples of this, such as Admiral Nurses educating care home staff (Williams, 2012) and raising dementia awareness in primary care settings (Thompson & Devenney 2007). However, in general, there was a not a great deal of literature relating to this aspect of their role and it was not clear how much emphasis they placed on it or how they balanced their consultancy and case work roles.

Therapeutic relationship

A number of the studies referred to therapeutic relationships between Admiral Nurses and carers of people with dementia (Dewing & Traynor 2005; Stamper & Taylor 2011). It was not always clear how this was defined or operationalized in practice but it seemed to encompass the development of a relationship that involved empathy, trust and mutuality and that facilitated the development of skills in the carer. The caring and approachable nature of the Admiral nurse provision was stressed in a number of studies and for many carers the opportunity to develop a relationship with an Admiral Nurse they knew well was key to feeling supported and understood (Clare et al, 2005; Kendall-Raynor, 2009; Maio, 2011; Woods & Algar, 2009). In Maio's (2011) carer satisfaction survey the carers were asked what attributes they associated with Admiral Nurses. Of those who responded, 96% believed the Admiral Nurses were good listeners, 93% said they were good at building trust and establishing a good rapport and 93% said they were good at showing compassion, respect and understanding. These attributes are clearly important for carers and integral to developing the "friendly" relationship the carer's value (Claire et al, 2005). However, although this relationship appeared to be important to carer the impacts or outcomes that resulted from the establishment of a good relationship were less clear. Moreover, it was noted by one author that the development of a therapeutic relationship could be jeopardised by fast turnover of personnel or overstretched resources (Clare et al, 2005).

5.2 Admiral Nurses within the health and social care system

Dementia UK suggests that Admiral Nurses should work collaboratively with other health care professionals and organisations to facilitate co-ordinated care provision (http://www.dementiauk.org/what-we-do/admiral-nurses/what-admiral-nurses-do/). We found several references in the literature to collaborative working. For example Burton & Hope (2005) wrote about a collaborative working relationship with social services, Greenwood & Walsh (1995) about "strong links with allied services" and Claire & Willis (2005) reported that the Admiral Nurse "liaises with all the agencies concerned with the person with dementias care". However, the extent, or impact, of such collaborations was not fully explored or described. There were examples of barriers to collaborative working, with reports of tensions between the general practitioner (GP) and Admiral Nurses, a lack of communication with the care manager (Clare et al, 2005), and confusion amongst Admiral Nurses and community psychiatric nurses (CPNs) over the boundaries of their roles (Woods & Algar, 2009); but overall there was limited information about how other health care professionals viewed Admiral Nurses or the way in which the Admiral Nurses worked with others in specialist mental health teams and primary care services. We found non-research literature to suggest that Admiral Nurses are employed in acute hospital settings and care homes (Williams, 2012), and that they run a telephone help line (Armstrong 2008), but there were no detailed descriptions or evaluations of these initiatives.

A number of the included studies and reports explored issues around referral mechanisms and caseload size. Referrals to the Admiral Nursing Service were reported to come from a variety of health and social care professionals including social workers, GPs, CPNs and psychiatrists (Woods & Algar 2009; Clare et al 2005); in addition in some models of the service carers were able to self-refer to the service. Despite the fact that Admiral Nurse teams are generally small, and often cover wide geographical areas (Clare et al 2005), there was evidence to suggest that Admiral Nurses often felt unable to refuse new cases (Burton & Hope, 2005), and that case loads were sometimes too large for them to provide meaningful support to carers (Kendall-Raynor 2009; Clare et al 2005). Two authors reported carer concerns that high demand on the service could lead to long waiting lists or long gaps between visits (Clare et al, 2005) and suggestions that the service was "patchy" (Kendall-Raynor, 2009). There was also evidence that the long wait for a first appointment with an Admiral Nurse in some locations resulted in carers turning to other services, such as mental health teams, who because of greater capacity were able to respond more quickly (Clare et al, 2005). One non-research item referred to the ideal case size (suggesting a case load of 20-25) (Kendall-Raynor, 2009)

but overall there was little evidence to say what the optimal case size or frequency of contact would be.

There was evidence to suggest that Admiral Nurses were often working in a context in which carers were dissatisfied with many of the existing statutory services. For example, perceived problems with statutory services expressed by carers included poor service quality (Burton & Hope 2005), a perception that services were not responding to their needs or the needs of the person with dementia (Hibberd et al, 2008; Maio, 2011), complaints that day centres were "too loud and too noisy" and unable to cope with behavioural issues associate with dementia, problems with the quality of respite care (Butterworth 1995), and complaints from carers that supports groups were depressing (Quinn et al, 2012). In addition, there was criticism, by carers, of the support provided by primary care professionals such as GPs (Butterworth 1995; Maio 2011), and with social care (Armstrong 2001, Hibberd 2011).

5.3 Recurrent themes in the literature

Twenty two papers provided information for the thematic analysis. We identified three overarching thematic categories (see Figure 3) relating to Admiral Nurses:

1. Relational support, including the subthemes of carer-centred approach, individually tailored, and admiral nurse as friend.
2. Co-ordinating and personalising support, including the subthemes of facilitation, collaboration, and advocacy.
3. Challenges and threats to the provision of services by Admiral Nurses. Including the subthemes of caseloads, providing care across the dementia trajectory, defining the role, and relationship dynamics.

These themes are informed by theories of continuity of care (Fulop and Allen, 2000, Haggerty et al., 2003, Parker et al., 2009). More details of the evidence to support them can be seen in Appendix 6

Theme 1: Relational support

Theme 1 is termed relational support and it includes descriptions of the nature of the relationship that develops between the Admiral Nurse and the carer. It encompasses: carer-centred approach, individually tailored, Admiral Nurse as friend and on-going support.

One of the distinguishing characteristics of the Admiral Nursing service is their carer-centred approach and it has been suggested that this makes their role unique (Burton & Hope, 2005). There was evidence that carers welcomed a service which focused on them rather than the person with dementia (Clare et al, 2005); "the CPN is for mum, the Admiral Nurse is for me" (Woods and Algar 2009), "love the way the Admiral Nurse always emphasised that I was her patient, not my wife" (Clare and Willis 2005). It was suggested that by supporting the carer, Admiral Nurses are indirectly supporting the person with dementia (Keady et al, 2007) and helping to address the imbalance in the dementia care system (Greenwood & Walsh, 1995).

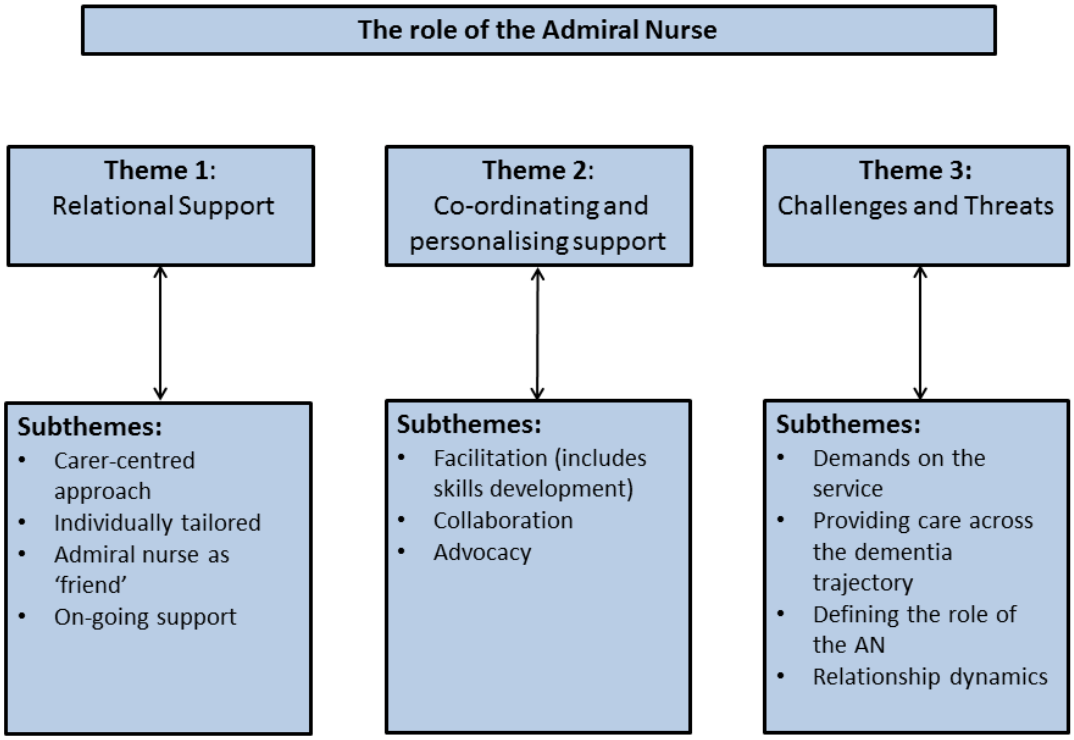

Figure 3: Themes and subthemes: this figure shows the three overarching themes and related subthemes that emerged from our analysis.

Relational support also included the delivery of individually tailored care (Keady et al 2007). This is highlighted by the carer who talked of the Admiral Nurse "entering her world" (Hibberd, 2011). There was also evidence that information was provided in a format that met the needs of the individual; "the nurse did not push me, told me only what I needed to know" (Clare et al, 2005). This personalised approach appeared to have positive impacts on the carers' wellbeing, with one carer describing the gaining of this knowledge as "coming out of a thick fog" (Clare et al, 2005).

There was evidence that carers valued interacting with a professional that they knew well. Admiral Nurses were seen as friends, for example being described as "a friend as well as a nurse" or "my anchor" (Clare et al, 2005) or as "life-saving" (Clare et al, 2005), "an angel" (Kendall-Raynor, 2009), an "excellent personality" (Maio, 2011) and "worth her weight in gold" (Woods & Algar, 2009). There is evidence that having a person to talk to and the feeling that "someone is taking notice" help to reduce the feelings of isolation that are associated with the caring role (Clare et al, 2005). It was suggested that the ability to develop such relationships was facilitated by the "provision of long term support through the dementia journey" (Greenwood & Walsh, 1995).

Theme 2: Co-ordinating and personalising support

Our second theme is termed co-ordinating and personalising support and it relates to the role of Admiral Nurses in coordinating, integrating and personalising care. It is reported that a component of the Admiral Nurse role was facilitation, which included organising support, providing information and advice and assisting carers to develop their own coping mechanisms (Clare et al, 2005; Meredith, 1998; Hibberd, 2011; Burton & Hope, 2005). The Admiral Nurse role also included collaboration with other services and health and social care professionals in order to provide support for the person with dementia and the carer. For example, liaising with memory clinics or social services (Burton & Hope, 2005), organising aids and helping to set up services such as day hospital places (Clare et al, 2005) and respite (Burton & Hope, 2005). However, at times carers felt that GPs, specialists and care managers did not work with or communicate with Admiral Nurses and this could be a barrier to management continuity (Clare et al, 2005). Admiral Nurses were also found to be acting as advocates for the carers. This included providing information about benefits that might be available (Woods & Algar, 2009) and acting as a "go-between" with other professionals (Maio, 2011). Advocacy also involved acting in a consultancy role to other health care professionals. For example, educating care home staff (Williams, 2012), and raising dementia awareness in primary care settings (Thompson & Devenney, 2007).

Theme 3: Challenges and threats to the provision of services by Admiral Nurses

Theme three relates to the challenges faced by Admiral Nurses in providing services and effective care. It includes the subthemes, demands on the service, providing care across the dementia trajectory, defining the role of the Admiral Nurse and relationship dynamics. There was evidence that there were often great demands on the service and the negative impact of this was reported from the perspective of both carers (Clare et al, 2005; Woods & Algar, 2009) and Admiral Nurses (Burton & Hope, 2005; Soliman, 2003). Carers reported that the number of visits had been reduced

(Clare et al, 2005) or withdrawn altogether (Woods & Algar, 2009), and one study suggested that high caseloads left nurses struggling to maintain the balance between casework and consultancy (Soliman, 2003). Deficiencies or problems with other statutory services also appeared to increase the demands on the Admiral Nursing Service. Providing support across the course of the dementia trajectory was reported by some to be one of the characteristics of the Admiral Nursing service (Greenwood & Walsh 1995, Burton & Hope 2005) but this could create a strain as more clients were assigned to the service (Burton & Hope, 2005). Another challenge to service provision related to a lack of clarity about the Admiral Nurse role. Clients were not always clear what the Admiral Nurse service was offering them; "cannot see any point to this service", "never really found out what the Admiral Nurse service was offering" (Clare et al, 2005). In addition, it was not clear what the service could realistically achieve or if the service had particular benefits for carers at particular points in the dementia trajectory.

Admiral Nurses also had to deal with the, sometimes difficult, relationship dynamics between the carer and the person with dementia. A number of papers described how the introduction of an Admiral Nurse might impact on the dynamic of the relationship between the carer and the person with dementia. It was suggested that Admiral Nurses might help to stabilise the relationship between the carer and the person with dementia (Hibberd 2011), for example by helping carers cope with the strain of changing family relationship dynamics as the person with dementia became increasingly dependent on the carer (Quinn et al 2012, Keady et al 2007, Burton & Hope 2005, Hibberd, 2011). However, one study highlighted the potential difficulties of balancing the differing viewpoints of the Admiral Nurse, the carer and the person with dementia (Quinn 2012).

5.4 Outcomes and effectiveness

In this section we look at the evidence relating to the effectiveness of Admiral Nurses and their impact on carers. This includes carer's health and well-being, satisfaction with Admiral Nurses and access to Admiral Nurse Services.

Carer health and well being

We identified only one controlled study evaluating the impact of Admiral Nurses on the health and well-being of carers. This study (Woods et al 2003) evaluated the impact of the Admiral Nursing service on carers using the General Health Questionnaire which tests for somatic symptoms, anxiety and insomnia, social dysfunction and severe depression for the carer (GHQ). A total of 128 carers were recruited who were either receiving help from Admiral Nurses or other mental health services,

such as CPN's and Memory clinics. There found no significant differences between the groups on the primary outcome measure (or its subscales) at eight month follow up, apart from anxiety and insomnia where outcomes were better for the Admiral Nurse group. However, both conventional and Admiral Nurse Services were associated with lower distress scores over the eight month period which suggests that carers benefited from support irrespective of the provider.

Carer satisfaction

A number of studies measured carer satisfaction with the services provided by Admiral Nurses. Clare et al (2005) looked at carer views on the emotional support and education provided by Admiral Nurses. In general responses were positive with 79.5% (n=399) of carers reporting that Admiral Nurses had fully understood their situation, and only 1% saying that the service was not at all helpful. Maio (2011) sent questionnaires to 82 carers in North Lincolnshire to explore their opinions on specific aspects of the Admiral Nurse role (including: provision of advice, suggestion of coping strategies, addressing the wellbeing of the person with dementia as well as the carer, collaborative working, development of skills, advocacy, and the provision of emotional, physical and social support). Data from the 30 carers who responded indicated that, amongst those who returned their questionnaires satisfaction with the service was high with carers scoring the provision of advice, the development of skills and the provision of emotional, physical and social support particularly highly. Stamper & Taylor (2011) sent a questionnaire to 82 carers in East Kent to assess whether carers considered that Admiral Nurses were meeting a set of specific criteria. The criteria included assessment and prioritisation of carer needs, whether appropriate action was taken to meet those needs, and whether clients were offered appropriate therapeutic interventions (such as emotional support, signposting to other agencies, education, information provision, risk assessment and stress and tension reduction strategies). Despite some variation in the percentages of positive responses, the majority of the specified criteria were being met. However, it was not clear how many carers had responded and the results should be interpreted cautiously.

Woods & Algar (2009) evaluated the Admiral Nurse Service in Flintshire in Wales using carer satisfaction questionnaires. The results reflect the findings in other surveys, the diversity of the Admiral Nurse role and the overall positive views with 91% of carers rating the service as "excellent". However, it should be noted that only 36% (n=22) of carers responded and the vast majority of the comments relate specifically to one Admiral Nurse and it was not clear to what extent the results might be generalised to other Admiral Nurse Services. Indeed, the findings of all the studies relating to carer satisfaction need to be considered in the context of low overall response rates.

Access to the Admiral Nursing Service

Several studies looked at access to the Admiral Nursing Service (Clare et al 2005, Woods & Algar 2009). In Clare et al (2005), the majority of carers found out about Admiral Nurses from their social worker or their GP and in Woods & Algar (2009) the most common sources of referral were CPN's, Psychiatrists and Social Workers. Clare et al (2005) went on to explore the ease of contact with the service and found that making and maintaining contact with the service initially was found to be easy in the majority of cases (95.7%), as was knowledge about the times Admiral Nurses were available (85.1%) and knowledge of who to contact in an emergency (75.5%). However, only just over half of the respondents knew who to contact outside of Admiral Nurse's hours (53.2%). One paper reported on a project run by Admiral Nurses to teach GP's and receptionists about the signs of dementia, how to manage the person and the services available (Thompson & Deveney, 2007). They found anecdotal evidence that the number of referrals increased after the training was administered.

5.5: What does current evidence tell us about the potential impact of Admiral Nurses?

In previous sections we have looked at what currently available evidence tells us about the scope and nature of the Admiral Nurse role, the key attributes of Admiral Nurses, how they work with other services and their impact on key outcomes such as carer satisfaction. It is important to consider this information in the context of what we already know from other evidence about carer's experiences of services and what they might need to support them. A recent systematic review investigated which support services individuals with dementia and their family carers perceived as helpful (Bunn et al 2012). The review, which synthesised over 100 qualitative studies (41 of which were from the UK) involving people with dementia and their family carers, found that, although there had been improvements in access to specialist diagnostic services, support after diagnosis was often perceived as inadequate, particularly by family carers. There was a paucity of post-diagnosis specialist support services and a lack of information and support for carers. In Table 3, we compare evidence from that review with what we know about the services provided by Admiral Nurses.

Table 3: The potential impact of Admiral Nurses

Carers want: Continuity of care/flexibility
• Admiral Nurses (AN) provide service that is individually tailored to each carer (e.g. might include grief counselling (Hibberd, 2011, Soliman, 2003). • Continuity of care within the AN service stems from the development of the relationship between the nurse and the carer (Clare et al, 2005). • The development of this relationship is "integral to making the service valued" (Hibberd, 2011) and is interlinked with the wide range of emotional support provided, which is demonstrated in the literature.
Carers want: Information about aids and entitlements
• AN offers "education about access to benefits" (Armstrong 2001) to address issues with carers having "little knowledge of their entitlement" (Woods & Algar, 2009).
Carers want: On-going opportunities to talk to supportive professionals
• The Admiral Nursing service provides long term emotional support (Greenwood & Walsh, 1995) which can continue throughout and after the care home transition (Burton & Hope, 2005) and after death (Hibberd, 2011). • Long term support does have resource issues Kendall-Raynor (2009) states that "ideally admiral nurses would follow the person with dementia and their carers throughout the entire journey. But in reality, after some intensive work the nurses have to sometimes redirect their clients to other agencies".
Carers want: specialist support
• ANs are "specialist mental health nurses" (Dementia UK) • ANs "nursing skill and knowledge are valued by carers" (Hibberd, 2011) and they have a vast amount of dementia knowledge generally, which allows them to offer advice about specific problems (Quinn et al, 2011). • ANs receive regular continuing professional development which supports their clinical and academic learning. Hibberd (2011) • AN have consultancy role, which includes providing advice to carers, care home staff and primary care professionals (Thompson & Devenney 2007; Williams, 2012,) • ANs can act as an advocate for carers. (Maio, 2011)

Carers want: Signposting to appropriate statutory and voluntary services

- Providing information on which services are available and where to find the appropriate information is part of the AN role (Hibberd, 2011).
- 76% compliance to standard "signposting" to various statutory and voluntary services in the Kent Admiral Nursing Service (Stamper & Taylor 2011).
- AN provide information about & facilitate local support groups (Hibberd, 2011; Weatherhead, 2008).
- Provide information about respite (Burton & Hope, 2005) or day hospital placements (Clare et al, 2005).

Carers want: Individually tailored information

- ANs tailor the information given to the carer depending on their emotional state, for example "I was confused about Mother and the Admiral Nurse did not push me, told me only what I needed to know" (Clare et al, 2005) or of Admiral Nurses making suggestions "quietly without being pushy" (Maio, 2011).

Carers want: peer support may be beneficial

- A number of examples of ANs providing information about or facilitating local support groups (Weatherhead, 2008, Hibberd, 2011, Pinto-Banerji 2002, Sarna & Thompson 2008).
- "Joe's Club" support group run by ANs (Braker 2007) which they say is showing positive impacts on carer's lives by helping develop support networks.

5.6. The effectiveness of community based dementia support

The synthesis in phase 1 allowed us to explore the range and focus of the Admiral Nurse role. However, assessing the impact of Admiral Nurses is challenging as the empirical evidence base is relatively limited, the Admiral Nursing service is a comparatively small provider, and because the Admiral Nurse role appears to have evolved and developed in response to changing contexts. In this section we situate our knowledge of the role and scope of Admiral Nurses in the context of other community based interventions for the family carers of people with dementia. Community based interventions considered in this section include case management, psychosocial and educational support and multi-component interventions. Amongst the included published reviews the most frequently reported carer outcomes were depression and caregiver burden, and the most commonly reported outcomes for people with dementia related to admission to hospital or move into long-term care. Greater detail about the individual reviews can be seen in Appendix 5. In this section we begin by looking at the impact of the interventions on caregivers and then move on to discuss the impact on people with dementia.

Caregiver depression

Seven reviews measured the impact of some form of community support on depression in carers of people with dementia (Brodaty et al 2003, Hall & Skelton 2012, Parker et al 2008, Pinquart & Sorenson 2006, Schoenmakers et al 2010, Smits et al 2007, Thompson et al 2007).

Case Management

Two reviews (Peacock & Forbes 2003, Schoenmakers et al 2010) looked at the impact of case management on depression in carers. Neither review found a significant reduction in depression although one (Schoenmakers et al 2010) found a non-significant reduction in symptoms of depression in caregivers.

Psychosocial

Two reviews looked at the impact of psychosocial interventions (e.g. skills training, psychotherapy, counselling) on caregiver depression (Brodaty et al 2003, Shoenmakers et al 2010). Brodaty et al (2003) reported that psychosocial interventions led to a modest but significant reduction in psychological morbidity in carers. In contrast Schoenmakers et al (2010) found no significant reduction in caregiver depression. However, they suggested that this might be accounted for by the variety of programmes tested and how regularly the programmes were administered.

Education

Three reviews included studies that evaluated the impact of educational interventions on caregiver depression, two of which (Pinquart & Sorenson 2006, Thompson et al 2007) found a significant reduction in depression. Pinquart & Sorenson (2006) report a reduction in caregiver depression after a psychoeducational intervention involving structured presentation of information. They suggest that interventions that require active participation (such as role playing) had the most positive effect. Thompson et al (2007) explored the impacts of group or individually administered educational interventions. They pooled five studies in a meta-analysis and found that although there was a reduction in depression in carers in both groups this was only significant in those who received the group based intervention. Peacock & Forbes (2003) reviewed four studies on educational interventions but found no improvement in caregiver psychological well-being, including strain and depression.

Multi-component

Three reviews (Smits et al 2007, Pinquart & Sorenson 2006, Parker et al 2008) included a number of studies evaluating the impact of multi-component interventions on caregiver depression. Smits et al (2007) reviewed 25 studies, seven of which measured caregiver depression. Of those two demonstrated a significant reduction in depressive symptoms, two found no significant effects and one reported an increased rate of depression in the carers participating in a program offering support groups for caregivers and memory or music groups for people with dementia. Pinquart & Sorenson (2006) looked at the impact of both structured and unstructured multi-component interventions but found neither had a significant impact on caregiver depression. Parker et al (2008) suggest that multi-component interventions can have an impact on carer depression and highlight The New York University Study which spanned 19 years and which demonstrated positive effects on caregiver depression that lasted for up to 3 years (Mittelman et al 2004a, 2004b).

Other interventions

Cognitive behavioural therapy (CBT) is widely used within the health services and two reviews (Parker et al 2008, Pinquart & Sorenson 2006) included studies that looked at the use of CBT for people with dementia and their carers. One review (Parker et al., 2008) included one study of CBT for carers which found a short-term (six weeks) reduction in carer anxiety after a nine week CBT programme. However, the study had a high attrition rate which led to limited follow up after the initial six weeks. The other review (Pinquart & Sorenson 2006) reported that CBT had a significant

effect on depression and burden, but no significant effect on ability or knowledge and caregivers subjective wellbeing. Schoenmakers et al (2010) also included a study which tested whether enhancing the acquired communication skills of caregivers would decrease the psychological distress related to dementia care giving. The study demonstrated a weak effect insufficient to relieve burden and depression of the caregiver.

Caregiver burden

Eight reviews included a measure of caregiver burden (Brodaty et al 2003, Cooke et al 2001, Hall & Skelton 2012, Parker et al 2008, Pinquart & Sorenson 2006, Schoenmakers et al 2010, Smits et al 2007, Thompson et al 2007) and two (Hall & Skelton 2012, Pimouguet et al 2010) also included a measure of caregiver stress and strain.

Psychosocial

None of the three reviews that included an evaluation of psychosocial interventions (Brodaty et al 2003, Cooke et al 2001, Schoenmakers et al 2010) found a significant impact on caregiver burden. However, Brodaty et al (2003) undertook further analysis which they say indicates that the involvement of both the caregiver and the person with dementia are integral to a successful psychosocial intervention.

Educational

There was mixed evidence on the impact of educational interventions on caregiver burden. One review (Pinquart & Sorenson 2006) found that psychoeducational interventions significantly lowered caregivers' feelings of burden but two reviews (Parker et al 2008; Thompson et al 2007) found no evidence that psychoeducational interventions reduced caregiver burden.

Multi-component

The impact of multicomponent interventions on caregiver burden was explored in three of the included reviews, two of which found little reduction in carer burden. Caregiver burden was used as an outcome measure in 13 studies in Smits et al (2007). Although four studies found a reduction in carer burden this was only significant in one, and in one study there was an increase in subjective burden in the intervention group. Pinquart & Sorenson (2006) reached similar conclusions, finding that neither structured nor unstructured multi-component interventions had a significant effect on caregiver burden. One review (Parker et al 2008) suggests there is some evidence to suggest multi-

component interventions can reduce carer burden citing evidence from the New York Study (Mittelman et al., 2004a, Mittelman et al., 2004b, Roth et al., 2005)and the REACH studies (Gitlin et al., 2005, Gitlin et al., 2003, Eisdorfer et al., 2003, Burns et al., 2003). These interventions included family counselling and weekly support groups.

Other

Respite is a well-established intervention for people with dementia but there are few evaluations of its impact on carers. Schoenmakers et al (2010) reported two studies in which respite was combined with the provision of professional care support and found that respite care significantly increased caregiver burden rather than decreasing it. However neither were randomised controlled trials and it is possible that selection bias may have accounted for this finding. Pinquart & Sorenson (2006) pooled studies evaluating respite and concluded that respite demonstrated a small, but significant improvement in caregiver burden, depression and subjective wellbeing. However, it is not clear how many studies were included in the meta- analysis. They also report that an intervention involving counselling and case management to resolve pre-existing personal problems that complicate care-giving had a moderate but significant effect on burden. However, there was no significant impact on depression, subjective well-being, ability and knowledge and "symptoms" of care receiver (e.g. behavioural problems, cognitive deficits, negative affect and deficits in functional abilities).

Other outcomes that relate to the impact of caring for a person with dementia included subjective well-being (measured in two reviews), psychological well-being (one review), quality of life (one review), knowledge (four reviews), social outcomes (one review) and self-efficacy (two reviews). Both reviews that measured subjective well-being (Parker et al 2008, Pinquart & Sorenson 2006) found small but significant improvements after education based interventions, and a review of psychosocial interventions found some improvements on caregivers' psychological wellbeing (Cooke et al 2001). In the later the integration of a social component, such as support groups or social activities, appeared to increase effectiveness.

A review of case management (Somme et al 2012) found some impact on quality of life particularly if it was integrated into other health care services. Psychosocial interventions appeared to have a marginally positive effect on caregiver social outcomes (Cooke et al, 2001). There was weak evidence to suggest that psychosocial interventions had an impact on caregiver knowledge (Brodaty et al 2003), and that multicomponent interventions increased carers' feelings of competence (Smits et al 2007). Educational interventions increased caregiver knowledge (Pinquart & Sorenson 2006)

but did not appear to have a significant impact on measures of self-efficacy (Parker et al 2008, Thompson et al 2007).

People with dementia moving residence from their or a relative's home to a supervised or care home setting

Five reviews (Hall & Skelton 2012, Peacock & Forbes 2003, Pimouguet et al 2010, Pinquart & Sorenson 2006, Tam Tham et al 2012) looked at the impact of community based interventions on long-term care placement for people with dementia. Overall there was mixed evidence on whether community based interventions reduced or delayed a move into a supervised or care home setting for people with dementia.

Case management

There was some evidence to suggest that case management might delay moving the person with dementia to live in an institutional setting such as supervised/sheltered/care home/nursing home. Pimouguet et al 2010 concluded that case management can be effective in reducing time until or likelihood of any placement in long-term care for the person with dementia and Tam-Tham et al (2012) found some evidence of a short term reduction in long-term care placement. However, the reduction was no longer significant at 18 months. Peacock &Forbes (2003) found mixed evidence on the impact of case management on the rates of placing the person with dementia in an institution.

Psychosocial & educational

Brodaty et al (2003) found some evidence to suggest that psychosocial interventions prevented or delayed the admission of people with dementia to nursing homes. Seven of the 30 studies included in the review measured time until moving to a nursing home placement. Of those two studies found a significant impact on time to nursing home placement and two an insignificant, but longer median time until move to a nursing home. There was mixed evidence on the effect of educational interventions with one review (Pinquart & Sorenson 2006) finding no significant impact of the numbers of people with dementia moving to a nursing home and one (Peacock & Forbes 2003) highlighting a study by Brodaty et al (1997) that suggests that educational interventions do reduce the rate of admission to a nursing home. The strongest evidence related to the effect of multicomponent interventions with evidence from two reviews (Sits et al 2007, Pinquart & Sorenson 2006) that they significantly delayed or reduced admission to a nursing home; although Pinquart & Sorenson (2006) suggested that interventions needed to be highly structured to be effective.

Other

Peacock & Forbes (2003) report on a RCT of psychotherapy for caregivers with follow up at 12 months (Mittelman et al 1993) and three years (Mittelman et al 1996). The psychotherapy programme consisted of six individual counselling sessions that focused on communication and problem solving. The intervention group were required to a join a support group and had access to counselling and support at any time, whereas the control group received the normal level of care. They found that this intervention delayed the rates of admission to long-term care.

Hospital admissions of the person with dementia and services use

Case management

Two reviews (Tam-Tham et al 2012, Pimouguet et al 2010) assessed the impact of case management on hospital admissions of the person with dementia but neither review found a significant impact on rates of admission to hospital. Two reviews reported on other types of resource utilization. One (Peacock & Forbes 2003) reported on the MADDE study in which case management doubled the likelihood of carers using other support services and the other (Somme et al 2012) concluded that case management programmes did not significantly impact on health and social care resource utilization.

Method of delivery

Several reviews compared different methods of intervention delivery for community based interventions, for example comparing group based or individually administered interventions (Pusey & Richards 2001, Thompson 2007) or looking at the impact of using technology such as telephones or computers to deliver interventions (Pusey & Richards 2001, Thompson et al 2007, Schoenmakers et al 2010, Peacock & Forbs 2003). In general there was little evidence to say whether one method of delivery was more effective than another.

Types of people delivering the interventions

Most reviews provided little information about the type of person or professional delivering the intervention which was being evaluated, and it was, therefore, often not clear whether nurses were involved. One review (Hall & Skelton 2005) evaluated the role of occupational therapists in supporting care givers of people with dementia and compared them to other professional groups. They found insufficient evidence to draw any conclusions about the effectiveness of interventions

delivered by occupational therapists or multidisciplinary teams. The review included two studies which involved nurses. One was a controlled study comparing Admiral Nurses to community mental health teams (Woods et al 2003), and one was an RCT looking at the possible benefits of psychosocial intervention training for community mental health nurses. The aim of the training was to equip nurses to help enable caregivers to cope with caring for a person with dementia (Moniz-Cook at al 2008), and they reported a significant improvement in the level of caregiver anxiety.

6. Discussion and conclusions

6.1 Discussion

Summary of main findings

Phase 1

We found 35 papers, reports or articles relating to the scope, nature and impact of Admiral Nurses; only nine of which were classified as research. We found no evidence relating to the Admiral Nurse telephone help line and the evidence presented relates to those Admiral Nurses working in locally organised teams. Although the research base is limited there were core attributes that characterised the Admiral Nurse role. This included a focus on the family carer as the client, and the ability to assess carer needs, provide therapeutic interventions, develop a therapeutic relationship and offer information, skills training and education. The ability to establish a good therapeutic relationship with the carer was viewed as important, by both carers and Admiral Nurses, and the caring, approachable and friendly nature of the service was a recurring theme in the literature. Although it was reported that providing advice to other health care professionals was a part of the Admiral Nurse role it was not clear the priority level this was given or the manner in which the nurses balanced their consultancy against their casework roles. There was also evidence to suggest that increasing caseloads and the wide range of demands on the Admiral Nursing Service posed particular challenges for sustaining continuity of contact and therapeutic relationships. There was only one controlled evaluation of the Admiral Nursing Service (Woods et al, 2003). This study found no evidence that Admiral Nurses improved carer outcomes in comparison with conventional services although both services were associated with lower distress scores in carers.

The service offered by Admiral Nurses is unique in dementia specialist care in that the client is explicitly the carer rather than the person with dementia. Although some of the literature looked at the impact this might have on relationships (Quinn et al, 2012) in general the implications of having a carer, who is potentially a well person, as a client were not fully explored. Several papers did refer to the psychotherapeutic work being done by Admiral Nurses (Hibberd 2011; Soliman 2003) and many referred to the emotional support provided by Admiral Nurses, but, in general, there was a lack of information about how Admiral Nurses used their therapeutic skills. The review demonstrates the breadth and scope of the Admiral Nurse role but, apart from the focus on supporting the carers of people with dementia, there appears to be no common agreement about what this role can and cannot achieve at different points of the carer experience of supporting someone living and dying

with dementia. One paper described the development of a set of competencies for Admiral Nurses (Dewing & Traynor, 2005) but it was not clear to what extent this framework was adopted by Admiral Nurses or how it was used to guide current practice.

There is evidence to suggest that the scope of influence of Admiral Nurses extended into other settings beyond the community (e.g. working in acute hospitals and care homes) but there were, no evaluations of these services and it was not clear how the role differed between the different settings. Admiral Nurses appeared to receive referrals from a variety of health and social care professionals, which suggests that they are recognised by other professionals. There was, however, a lack of information on the ways in which Admiral Nurses worked with other services or professionals, the length of time required before they became an established part of the system of care, the perceptions or expectations other providers or public service commissioners had of the role and the ways in which respective roles and responsibilities were negotiated.

Phase 2

The evidence relating to the effectiveness of community based interventions for family carers of people with dementia was mixed. We found 13 previously published systematic reviews evaluating a range of community based support. In general the evidence of effectiveness for most interventions was weak. However, although efficacy of interventions was difficult to establish caregivers were often reported to express high levels of satisfaction with community based interventions (Schoenmakers et al 2010). Admiral Nurses are involved in psychosocial and educational interventions and there was some evidence that these types of interventions could reduce depression in carers. Moreover, there was evidence from a longitudinal study (Mittelman et al., 2004a; Mittleman et al., 2004b; Roth et al., 2005) that on-going counselling and support may be beneficial to carers. Most of the systematic reviews did not specify who delivered the interventions and so it was not clear to what extent nurses were involved. However, the interventions being evaluated, such as case management, psychosocial interventions and education, are within the remit of Admiral Nurses. Although Admiral Nurses do not have an official case-management role, they are involved in case work and liaison with other services.

Comparison with existing literature

Previous research (Bunn et al 2012) suggests that key needs for family carers and people with dementia include the early provision of information about financial aids and entitlements, the opportunity to talk to supportive professionals, signposting to appropriate statutory and voluntary

services and specialist support that is flexible, and sensitive to the needs of individuals. Literature on specialist community nurses has also found that both patients and carers valued services that improved access to health care, provided psychosocial support, and improved communication with health professionals (Sargent et al., 2007, Sheaff et al., 2009). Such findings appear to fit with the scope and nature of the support being provided by Admiral Nurses and, indeed, a number of the evaluations of Admiral Nurse Services reported high levels of carer satisfaction (Clare et al 2005; Maio 2011; Woods & Algar 2009).

However, assessing the impact of Admiral Nurses is hampered by a lack of clear goals for the service. Although there are clearly common values, including the unique focus on the carer, the attributes and development of the role appears to be affected by the local context in which the nurses work, the nature of existing services and the size of Admiral Nurses' caseloads. It has been suggested that in the absence of clear or realistic goals, roles become shaped by the expectations of stakeholders, such as managers and nurses in the role, resulting in wide variations in how roles are interpreted and used (Griffiths et al., 2013). A survey of dementia specialist nurses in in-patient settings in the UK found a wide range of interpretations of the nurse specialist role, of activities undertaken by specialists, and of expected impacts (Griffiths et al 2013). This lack of role clarity is not unique to Admiral Nurses or dementia care but has been a concern for many specialist nurse roles (Aranda and Jones, 2008). Indeed it has been suggested that a lack of role definition has impacted on the effectiveness of community matrons (Forbes et al., 2002, Chapman et al., 2009). However, Admiral Nurses are individually commissioned by the employing organisations and this may account for differences in service provision.

Dementia is a long-term condition with periods of stability but an overall course of decline in cognition and memory accompanied by impairments and problematic behavioural symptoms and there is evidence that carers appreciate on-going support (Bunn et al 2012; Brodadty 2003). Admiral Nurses provide support through on-going case work, however the optimum number of carers to receive this case work to whole time equivalent Admiral Nurses has not been established. Only one paper (Burton & Hope 2005) explored some of the factors that guided decisions about whether or not to accept a referral but it appeared that nurses found it difficult to refuse referrals when, as was often the case, potential clients had complex emotional and practical needs. These issues relating to work load are not unique to dementia care and many of the findings of the review parallel those on the introduction and role of the community matron (Drennan et al., 2011). Community Matrons were introduced to provide specialist nursing support to vulnerable people. There is evidence that as recognition of the expertise and support they were able to offer became more widely understood

they also experienced difficulties sustaining input over time (Sargent et al., 2008). Also the roles of both Community Matrons and Admiral Nurses are shaped by the limitations or deficiencies in other services. This can mean that the role evolves to provide services and support to compensate for the absence of other services rather than providing one that is discrete and standalone (Burton & Hope 2005).

Strengths and limitations

We conducted a systematic and rigorous search for literature relating to the scope and effectiveness of Admiral Nurses. In addition, we have evaluated evidence relating to Admiral Nurses in the context of what is known more generally about the effectiveness of community based support for people with dementia and their family carers. As such this review provides a baseline to inform future research on the role and effectiveness of Admiral Nurses. There are, however, a number of methodological issues that could have a bearing on the validity of these results. We found only nine research reports or papers of which only four (Burton & Hope 2005, Dewing & Traynor 2005, Quinn et al 2012, Woods et al 2003) had been published in a peer review journal. Moreover, most of the available literature is descriptive and there has been little work undertaken to evaluate outcomes for carers or to evaluate the specific interventions they provide. In addition current research has focused on the experiences and perceptions of Admiral Nurses or on carer satisfaction with the service. There is a little evidence relating to the way they work with other health and social services or how they are perceived by other health professionals.

Although a number of evaluations of Admiral Nurses reported high levels of carer satisfaction with the service the response rates to the questionnaire surveys were generally low and the findings often related to small numbers of Admiral Nurses. The extent to which the findings can be generalised beyond a specific service or individual nurses is not clear. In addition, although the qualitative literature suggests the responsiveness and adaptability of the role is a particular strength, this variation in the role between different contexts makes meaningful comparisons with other services difficult. Moreover, given the various professional and non-professional sources of support and help available it can be difficult to identify and evaluate the particular contribution of the Admiral Nurse.

Dementia is a condition that gets progressively worse and many carers will have complex physical, psychological and practical problems. The issues involved in evaluating nursing care in such complex circumstances are similar to those identified by researchers evaluating the impact of nurses providing end of life care for cancer (Corner et al., 2003). Current measures may not adequately

address the complexity of evaluating nursing interventions in deteriorating conditions. Similar methodological issues were apparent in the review of reviews. Despite the fact that we found 13 systematic reviews evaluating community based interventions these provided little evidence of which interventions are effective and how community support for people with dementia and their carers should best be delivered. Many of the reviews found little impact on carer burden or depression which might suggest interventions are ineffective and not worth investing in. However, caregivers often express high levels of satisfaction with such support and the lack of evidence of efficacy may, in part, be due to methodological problems with the outcome measures used in these studies. Depressive symptoms are one of the most widely used outcomes in caregiver intervention studies. Although there is a substantial prevalence of depression in caregiver samples not all carers will have depressive symptoms (Sinclair, 2006) and it may not be the most appropriate outcome to measure. In addition, some widely used measures of caregiver burden may not be sensitive to change following psychosocial interventions and may require refining (Katon et al., 2012). Furthermore, many of the measures focus on carer burden and depression there are a paucity of measures of positive capacity or satisfaction (Katon et al., 2012).

6.2 Conclusions

Much of evidence on the scope and role of Admiral Nurses is descriptive in nature. Few studies provide evidence of outcomes for carers or evaluate the specific interventions that Admiral Nurses provide. Although there is a larger body of work evaluating the effectiveness of community based interventions for people with dementia and their carers the effectiveness of many of these interventions is not clear. However, carers often express high levels of satisfaction with such support.

Based on our findings, we offer the following recommendations for practice and research.

Implications for practice

Based on our findings, we offer the following recommendations for policy and practice.

- Descriptive and qualitative evidence suggests that Admiral Nurses are valued by family carers but the impact of their work is not so clearly established. There is a need to define outcomes that can help organise the service and inform future service delivery.
- Increasing caseloads and the wide range of demands on Admiral Nurses may impact on the service they can provide and there is a need for realistic, and common, goals about what the service can and can't achieve.

- There are relatively small numbers of Admiral Nurses covering large geographical areas and there is evidence that services may be overstretched. There may be a need to reconsider the way the service works with other services and for which groups and at what stage in the dementia trajectory efforts should be focused. There is currently little evidence relating to optimal caseloads or frequency of contact.
- The Admiral Nurse role has common attributes and areas of practice however the absence of clearly articulated goals and shared objectives means that how the service is delivered is subject to the geographical location of the service and the needs of the host organisation and local area.

Implications for research

- The literature reviewed suggests that context, the needs of the host organisation, and practitioner experience and focus have shaped how the role is delivered in different settings. Future research should consider what the Admiral Nurse role should achieve at different stages of the dementia trajectory and what outcomes are meaningful at service and individual levels of care. Research designs that draw on realist methodologies of what works when and with what outcomes may offer more scope for judging effectiveness
- There appeared to be a good fit between evidence relating to what carers of people with dementia want from services and the role of the Admiral Nurse. However, there has been little work undertaken to evaluate the specific interventions Admiral Nurses provide.
- Although there was some evidence to suggest that the scope of influence of Admiral Nurses extended into other settings beyond working with people in the community (e.g. working with acute hospitals and care homes) there are no formal evaluations of these services.
- There is a lack of information of how Admiral Nurses' work with other services e.g. GPs, Community Mental Health Services. There is a need to investigate the contribution of Admiral Nurses from the perspective of other stakeholders such as statutory and voluntary service providers and commissioners.
- Although consultancy and education of other health care professionals appears to be a part of the Admiral Nurse role this is not well described in the literature. Further work is needed to establish the scope and impact of this aspect of their role.
- The unique contribution of Admiral Nurses is their focus on the carer.

- Current literature provides limited information about the needs of clients that Admiral Nurses work with. Further work may be needed to look at the profile of carers that Admiral Nurses support and to understand what aspects of carers' needs the service addresses.
- There are well documented methodological problems associated with evaluating complex interventions in the context of people who have deteriorating conditions. Future evaluations should take these into consideration.

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Appendix 1: Search Strategy

Undertaken: 19th November 2012

Search 1: Admiral Nursing

Scopus

"admiral nurs*" (in Title-Abs-Key-Auth)

CINAHL

Search terms: admiral.ti and (nurse OR nursing OR nurses).ti

Pubmed

Search terms: admiral AND (nurse or nurses or nursing)

NHS Evidence

Search term: Admiral nurses

Search 2: Admiral nursing and community support

CINAHL

(Admiral OR nurse specialist OR case management OR nurse role OR professional development OR nursing models OR advocacy OR competen* OR career* OR champion OR specialist*) (dementia OR alzheimer*) in box underneath. In top box TX All Text, then underneath TI Title

Pubmed

((Admiral OR nurse specialist OR case management OR nurse role OR professional development OR nursing models OR advocacy OR competen* OR career* OR champion OR specialist*[All Fields])) AND (dementia[TI] OR alzheimer*[TI])

Cochrane Library

(Admiral OR nurse specialist OR case management OR nurse role OR professional development OR nursing models OR advocacy OR competen* OR career* OR champion OR specialist*)(dementia OR alzheimer*) in Title, Abstract & Keywords

Scopus

TITLE(dement*) AND ALL (admiral OR nurse specialist OR nurse role OR professional development OR nursing models OR advocacy OR competen* OR career* OR champion OR specialist* OR case management)

Appendix 2: Quality Assessment Criteria

Study Type and Tool used	Scoring criteria
Surveys **Phase 1.** Adapted from CEBMa critical appraisal for surveys	Assessed on 12 criteria, which could be scored as 'yes, 'no', or 'can't answer'. 1. Did the study address a clearly focused question/ issue? 2. Is the research method (study design) appropriate for answering the research question? 3. Is the method of selection of the subjects (employees, teams, division, organisations) clearly described? 5. Was the sample of subjects representative with regard to the population to which the findings will be referred? 7. Was a satisfactory response rate achieved? 8. Are the measurements (questionnaires) likely to be valid and reliable? 9. Was the statistical significance assessed? 12. Can the results be applied to your organisation?
Controlled trial **Phase 1.** Cochrane Risk of Bias Tool	Assessed on six criteria. **Sequence generation.** E.g. Was the allocation sequence adequately generated? **Allocation concealment.** E.g. Was allocation adequately concealed? **Blinding of participants, personnel and outcome assessors.** e.g. Was knowledge of the allocated intervention adequately prevented during the study? **Incomplete outcome data.** E.g. Were incomplete outcome data adequately addressed? **Selective outcome reporting.** E.g**.** Are reports of the study free of suggestion of selective outcome reporting? **Other sources of bias.** E.g. Was the study apparently free of other problems that could put it at a high risk of bias?
Qualitative. **Phase 1.** Spencer and Ritchie	Assessed on nine criteria, which could be scored as 'fully', 'partly', 'not at all' or 'not clear'. ***Scope & Purpose***, e.g. clearly stated research question, clear outline of theoretical framework, underlying purpose clear, adequate description of the context in which the research was carried out (clearly stated hypothesis, explicitly stated or implied frame of reference) ***Design,*** e.g. discussion of why particular approach/method was chosen ***Sample,*** e.g. adequate description of sample used and how the sample was identified and recruited, adequate size for design used/ study objectives, selection criteria made explicit, inclusions and exclusion explained ***Data Collection,*** e.g. Systematic documentation of tools/guide/researcher role, recording method explicit ***Analysis***, e.g. documentation of analytic tools/methods used, evidence of rigorous/systematic analysis ***Reliability & validity,*** e.g. presentation of original data, interpretation/meaning/ significance assigned, how theories developed, triangulation with other sources, codes/ concepts/ themes checked by more than one researcher, evidence that participant accounts have been faithfully represented. ***Generalizability***, e.g. sufficient evidence for generalizability or limits made clear by author. ***Credibility/ Integrity/ Plausibility***, e.g. provides evidence that resonates with

	other knowledge, results/conclusions supported by evidence, Evidence "makes sense". ***Overall weight for reliability/ trustworthiness***: Low=one or more "not at all" value for the first five criteria above. Medium= at least 4/5 of the first five criteria above marked as "fully or mostly". High= all of the first five criteria above marked "fully or mostly" and none are marked "not at all" ***Overall weight for usefulness of findings for review***, e.g. To what extent does the study help us to understand one or more of the topics covered in the review? How rich are the finding? Has the study successfully enhanced our understanding of a new area/sample or enriched an old one?
Systematic reviews & Meta-analysis **Phase 2.** AMSTAR	Assessed on 11 criteria, which could be scored as 'yes;, 'no', 'can't answer' or 'not applicable'. 1. Was an 'a priori' design provided? 2. Was there duplicate study selection and data extraction? 3. Was a comprehensive literature search performed? 4. Was the status of publication (i.e. grey literature) used as an inclusion criterion? 5. Was a list of studies (included and excluded) provided? 6. Were the characteristics of the included studies provided? 7. Was the scientific quality of the included studies assessed and documented? 8. Was the scientific quality of the included studies used appropriately in formulating conclusions? 9. Were the methods used to combine the findings of studies appropriate? 10. Was the likelihood of publication bias assessed? 11. Was the conflict of interest stated?

Appendix 3: References to included studies

Phase 1

Research/Audit

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Appendix 4: Details of included literature

Admiral Nurses (Phase One) Total number of papers: 35

Research/audit= 9

Study	Aim	Participants	Method	Results/ outcomes
Burton & Hope (2005)	Examine individual decision making processes & factors influencing Admiral Nurses (AN) referral management	2 AN who had managed the 16 case files that were reviewed	Phase 1) Case file analysis to identify appropriate cases over a 6 month period to use for detailed exploration. Phase 2) Structured interviews with ANs	4 general themes about role emerged: 1) complexity of carers situation, 2) AN's perception of their specialist role, 3) mode of referral and information received, 4) cross-functional working/ trust wide provision Role - predominantly supportive & educational role rather than case management. Needs of the person with dementia monitored to observe the impact on the carer
Clare et al (2005) (unpublished report)	Evaluate carers' views on the achievement of service standards 1, 2 and 3. (*Standard 1*: Access to the AN Service. *Standard 2*: All referrals accepted & dealt with according to agreed criteria. *Standard 3*. Assessment: ANs will use the AN Needs Assessment Schedule to assess carers' needs when undertaking intensive work.	Carers on caseload of 13 ANs. 1607 potential Participants. 529 provided data. Response rate 33% 65% of carers lived with person with dementia, 71% female, 65.5% spouses, 82% White British	Questionnaire survey (sent to teams in different parts of England).	4 key aspects of carers' experience of the AN Service: **Obtaining information about the Service** • most found out about AN's from medical professionals (social workers, followed by GP's) • 2/3rds had received a leaflet about service- most given leaflet by the AN. **Making and maintaining contact with the Service** • 95.7% reported no problems contacting AN • 4.2% experienced difficulties contacting the service. (Reasons included staff shortages, no-one answering phone, waiting list) • Maidstone, Medway & Swale had highest proportion of delays in contact (13.2%) • 47% had been in contact with an AN for a year, 22% between 6-12 months • Perceived benefits of having earlier access (improved support and help, information & understanding, opportunity to talk to someone outside of the family) **Getting in touch with the Service** • 85.1% of people knew times AN available. • 75.5% knew who to contact in an emergency. • 53.2% knew who to contact out of AN hours • Time lapse between contacting the AN and the AN replying: 85.5% of

				respondents 1-2 days, 9% 3-4 **Working with the Admiral Nurse** • 96% put at ease at initial contact • Positive feedback: AN caring, helpful & supportive, knowledgeable, provides information & useful practical advice. Highly professional, efficient and courteous, high quality services. Valued the personal attributes. Overworked. • Negatives: difficulty talking to stranger, variability and staff changes, lack of privacy, felt under scrutiny. • 79.5% felt AN "fully" understood their needs • 73.6% felt AN "fully" understood needs of PWD • 67.5% felt AN fully worked with them to address their concerns. • 63.2% felt AN 'fully' addressed concerns of the PWD.
Dewing & Traynor (2005)	To work collaboratively with the practitioners to develop a competency framework that reflects the needs of the AN Service.		Action research Included: 1) Scoping exercise, 2) Themes shared with ANs 3) Development of competencies. 4) Pilot of draft version. 4) Developed scene for implementation.	Eight key competencies developed: 1. Therapeutic work (interventions) 2. Sharing information about dementia and carer issues 3. Advanced skills assessment 4. Prioritizing work load 5. Preventative and health promotion 6. Ethical and person centred care 7. Balancing the needs of the carer and the person with dementia 8. Promoting best practice
Hibberd (2011) PhD Also incorporates: Hibberd et al (2009)	Exploration of the meaning of family-centred admiral nursing for carers	<u>Strand 1</u> Admiral nurses: 27 out of 49 contacted responded. Carers: n=8 <u>Strand 2</u> Stakeholders: 18 (2 via e-mail/telephone interview, 5 through e-mail). Carers: 20	Mixed methods Appreciative inquiry. Included questionnaire to all ANs, telephone interviews with carers, photographs and narratives and focus groups with carers, ANs and other relevant stakeholders.	**Results for questionnaire to ANs (n=27)** Values of practice development: • 93% attend clinical supervision , 59% think it extremely beneficial • 93% attend peer group supervision, 55% think it extremely beneficial • 70% work as part of a multi-disciplinary team 5 points drawn from preliminary data: empowerment, negotiation, facilitating, information and partnerships. **Carer interviews (two sets 1 n=8, 2 n=9)** • 4 themes relating to changing nature of relationships: stabilising the relationship between the carer and the PWD, stabilising family relationships, professional relationships that stabilise, stabilising relationships to move on. • Professionals often unaware of the emotional wellbeing of the carer **Focus Groups**: Round 1:11 groups, 93 participants (carers, dementia patients, AN's and stakeholders). • 40 values emerged from the focus groups which were categorised into four

		Patients with dementia: 6		headings: organisations/partnerships, AN attributes and qualities, meeting the needs of the carer and person with dementia, AN clinical skills. **Carer interviews (n=9)**. . **Round 2:** 8 groups, 60 participants (carers, dementia patients and stake holders). Recognition by carers that their relationships change throughout the caring trajectory. Summary: Co-construction of AN principles and values: • *Attributes*. Friendliness, trust, caring, communicator, attitudes, honesty, flexibility and commitment. • *Meeting the needs of the carer*: communication, supporting relationships, flexibility, trust, honesty, continuity, sharing (of information, knowledge and skills), partnership, empowering, support (both practical and emotional) and accessibility. • *Knowledge and Skills*: communication, sharing, knowledge, consultancy, information (finding and developing), including the PWD, practice development, supervision, knowledge of therapeutic interventions and mental health. • *Working with Organisations*. Communication, accessibility, continuity, record keeping, autonomy, responsible, flexibility, collaborative working, knowledge and skills, partnerships and empowering.
Keady et al (2007)	To capture an autobiographical account of a family carers journey through the experience of dementia and the reflexive dialogue and shared planning that ensued with an Admiral Nurse	N=2. One Admiral Nurse and One Carers	10 guided autobiographical interviews for the carer to create a narrative.	Importance of constructing care from an autobiographical perspective.
Maio (2011)	Collect carers' opinions on their contact with local Admiral Nurse.	30 carers.	Carer satisfaction survey, North East Lincolnshire. 82 sent, 31 returned (37.5% response rate)	Length of contact- 30% for more than 2 years. 23% had over 20 contact times with AN. **Recognising the needs of the carer and the person they care for.** • 85% found AN very helpful or quite helpful for any of the following: (carers emotional/physical/social needs, PWD emotional/physical/social needs) **AN: building/ developing relationship with carer** • 96% good listeners • 93% good at building trust and establishing a good rapport/ showing compassion, respect and understanding

				• The remainders still considered them as quite effective. **Knowledge and skills of the AN** • Largely helpful in advising about signs and symptoms of dementia (82%) • Largely helpful in understanding impact of caring for PWD (79%) • Provision of activities- 54% very helpful, 23% quite helpful **Admiral Nurse Interventions** • 86% very helpful at providing advice, guidance and support, • Offering strategies to help with coping and caring – 71% very helpful • Address the wellbeing of the person cared for – 75% very helpful • Exploring the impact of dementia on the family as a whole – 71% very helpful • Working with others to provide co-ordinated care- 64% very helpful • Help build skills as care givers- 88% yes, 4% no, 8% not sure • Advocacy role- 68% yes, 24% not sure, 8% no **Significant differences that AN made to the carers (themes)** • Understanding the condition • Building carers confidence • Emotional support- reducing carer burden • Advocacy with external services • Time to listen, non-judgemental • Expertise, able to provide helpful advice and suggest coping strategies • Help not imposed and available when needed • Reassurance given by person-centred approach • Family work Problems: Service overstretched leading to longer waiting times for appointments and less availability for face-to-face meetings.
Quinn et al (2012)	Explore how health care professionals work with carers and patients in a triadic relationship	Six dyads (each a female caregiver and a male dementia sufferer and an AN). 12 people in total (3 ANs).	Semi-structured interviews. Thematic analysis.	Members of the triad are trying to negotiate the balance. Extends research demonstrating coalitions between various party members. Coalition between PWD and AN could impact on relationship between AN & carer.
Stamper & Taylor (2011)	To evaluate the extent to which the East Kent Admiral Nursing Service	82 carers randomly selected (response rate not clear)	Questionnaire sent to the carers.	**Criteria used for assessment:** 1. AN's undertake triage assessment during first interview with client (85% yes) 2. All needs identified from AN assessment will be

	(EKANS) is meeting the needs of its clients.		Assessed AN performance on a number of criteria	a. Addressed (94% yes) and b. appropriate action taken (80% yes) 3. The AN will prioritise any identified carers needs such as health promotion, stress management or other interventions as appropriate (86% yes) 4. All clients will be offered therapeutic interventions from their assigned AN as needs dictate. These interventions may include: a. support for emotional needs (91%), b. sign posting to other agencies (76%), c. providing written information (70%), d. education about diagnosis (83%) e. Stress and tension reducing strategies (76%) f. Any risks will be prioritised (87%) 5. The AN aims to enable the carer to better support the person with dementia using skills, training and education etc (82%) 6. The AN will seek to establish a good therapeutic relationship with the client (94%)
Woods et al (2003)	Evaluate outcomes for carers receiving the Admiral nurse service.	128 carers. New referrals to AN services, caregivers of people with a probable diagnosis of dementia, initially resident in non-institutionalised settings. London/North Thames area	Quasi-experimental design. Int: AN; Control:other specialist community based support. Carers interviewed x2, after referral, & 8 months Initial interview: Admiral Nurse (n=55), Control (n=73). Follow up: Admiral Nurse (n=43). control(n=61).	Main outcome measures: General Health Questionnaire (GHQ), Institutional placement & quality of relationship. GHQ – no significant differences on any subscale apart from anxiety & insomnia (less anxiety & insomnia in AN group p=0.038) There were no significant differences in institutional placements between the two groups.
Woods & Algar (2009)	An independent evaluation of the Flintshire Admiral Nurse service.	62 carers sent questionnaire, 22 responded (36% response rate) 7 carers interviewed separately	Carer satisfaction questionnaire and semi-structured interviews Interviews taped but not fully transcribed	**Carer satisfaction questionnaires** Help categories (rated as excellent): • General support/counselling (91%) • Dementia information (68%) • Practical Advice (86%) • Help with benefits (68%) • Carer treatment (59%) • PWD treatment (86%)

				• Referral to another service (81%) **Carer interviews** All were satisfied with the service. • Examples of how the ANS had supported carer varied but included things such as- practical support filling out forms, educating the carer, advice in how to deal with the PWD, coping strategies, liaising with professionals. • Some issues around lack of clarity of AN role • Some carers saw AN with the PWD and some alone. • Role of AN differed if she was the only regular service involved; e.g. she took blood pressure of both carers and people with dementia. • A theme that emerged in the interviews was the worry for the future and whether the service would continue. There was also the feeling that the carer would be lost without the support from ANS.

Non-empirical work= 23

Author & Paper	Journal of publication	What does the article refer to?	Brief description of content	Any information regarding specific role?
Service announcements				
Armstrong (2008)		A project involving an Admiral Nurse	Admiral Nursing direct. Uses case studies of recent calls to the service to show how it works	
"Friends of the Elderly"	Journal of Dementia Care		Announcement that the charity "Friends of the elderly" has appointed an AN to work in its care homes	Provision of emotional or psychological support, Provision of information
Kendall-Raynor (2010)	Nursing Standard	A project involving an Admiral Nurse	Virtual academy set up by Dementia UK, Canterbury Christ Church University and the Avante Partnership. Provides continuing professional development and a networking environment for AN through its website	
Publications for professionals				
Armstrong (2001) (Admiral nurse team leader)	Nursing Standard	Role of the Admiral Nurse	Covers a number of areas. Provides a descriptive section on the role of AN and what they should be doing to ease the burden of care. Suggests that remit includes:	Collaborative working, Guidance about accessing services, Provision of emotional or psychological support, Provision of information, Skilled

"The pressures felt by informal carers"			• supporting carers while ensuring that the person with dementia receives the best care possible • Consultancy, providing training, information and advice to health professionals • Working closely with CPN's, other professionals and voluntary organisations "it is very important that all of these agencies liaise and work together to complement, rather than duplicate each other's work" • Advising carer about financial issues • Working with carer to identify and deal with antecedent problems • Address issues around grief • Prepare carer for the time when residential care might be necessary	assessment of needs of carer/patient
Braker (2007) "Supporting carers of people with Dementia"	Nursing Times	A project involving an Admiral Nurse	Describes a support group called "Joe's Club" Based on the finding that meeting others who are in a similar situation reduces feelings of isolation, AN's have set up a club where carers can go and meet other carers and discuss their experiences.	
Jackson (2008) "Spreading the word"	Mental Health Today		Admiral nurses aiming to explore the issues with BME's not accessing services for dementia.	
Kendall-Raynor (2009) (on behalf of John Suchet) "Admiral nurses are doing such a good job there should be many more of them"	Nursing Standard	The role of the Admiral Nurse	Writes that: • Every dementia carer should have access to specialist support • Deals with a case load of up to 35, although 20-25 would be optimum. • The provision of dementia care services, such as Admiral Nurses, is extremely patchy and there needs to be an increase in funding	
Meredith (1998) (journalist) "Living with Alzheimers"	Nursing Times	The role of an Admiral Nurse	Writes that: • AN help to empower families effected by dementia	

			• Role of AN unique • Proactive • Being available for longer term work is important but the key is to avoid dependency and develop the carers support network • AN role exports secondary skills into a primary care setting, supporting the whole gamut of professional activity from pre-diagnosis through community care, placement and beyond.	
Pinto-Banerji (2002) "Caring for the carers"	Nursing Standard	The role of an Admiral Nurse	Describes how she liaises with other professionals including social services, primary care teams, voluntary organisations, local carer groups and Jewish groups	Collaborative working
Sarna & Thompson (2008) "Admiral nurses' role in a dementia carer's information programme"	Nursing Older People	A project involving an Admiral Nurse	The Carer's programme in Central and North West London. Run by Admiral Nurses. 8 week programme. Works with variety different organisations. Main aim to inform carers of medical, psychosocial and legal aspects of dementia. Aid planning. Promoting communication skills. Link carers with support group. Includes and evaluation of program	Guidance about accessing services
Thompson & Devenney (2007) "Training in dementia for primary care professionals: the role of the Admiral Nurse"	Primary Health Care	A project involving an Admiral Nurse	Phase 1: six workshops which were offered to GP practices, which covered a large range of topics. Workshops open to all primary care teams (doctors, nurses, receptionists) Phase 2: training undertaken in respective surgeries. Each package was tailor made to each surgery. Family carers were involved as trainers "Anecdotal evidence from the project team suggests that the training improved the quality and number of referrals from surgeries to Admiral Nurses. Doctors now frequently telephone to liaise with an Admiral Nurse about a particular situation, enhancing collaboration. A memory clinic is running and referrals appear more appropriate, with relevant tests being done by GP's prior to the patients attending the appointment."	Collaborative working

Weatherhead (2008) "Admiral nurse responds to dementia strategy consultation"	British Journal of Neuroscience Nursing.	The role of an Admiral Nurse	Written by an Admiral nurse. Lists roles. "Admiral nurses currently work in a number of ways to support early intervention: • Providing education to GP's • Working with staff in acute care settings in improving understanding about dementia care and carers' needs. • Developing practice within care homes • Introducing and supporting the use of life story work to improve understanding of dementia for both carers and health professionals. • Facilitating education and information groups for carers, people with dementia and health professionals within a range of settings"	Collaborative working, Developing carers skills, Provision of emotional or psychological support, Provision of information, Skilled assessment of needs of carer/patient
Weatherhead (2009) "Face to face"	Nursing Older People	The role of an Admiral Nurse	Writes that ANs • providing education, advice and support to families, carers and people with dementia • Have a strong education element in role	
Williams (2012) "Admiral nurses in dementia care"	Nursing and Residential Care	The role of an Admiral Nurse	Describes role working in a nursing home. • Provides training, assessment and advice • Responsible for implementing and evaluating MHL framework • Act as champions for best practice and ensure a person centred approach • Support relatives of residents	Collaborative working, Promoting positive approaches
Other journals				
Butterworth (1995) "The family caregiver's perspective"	Journal of Mental Health	Role of the Admiral Nurse	Minimal information. Written when AN service was just starting.	Provision of information
Ghiotti (2009)	Dementia	A project involving an Admiral Nurse	DELAP. The project began at the same time that an AN service was set up in Redbridge.	Provision of information

"The Dementia End of Life Care Project (DeLCaP): Supporting families caring for people with late stage dementia at home"			They took on a part-time AN alongside the project to provide information through training and support to help them plan ahead. No information about the role of the AN within the project.	
Greenwood & Walsh (1995) "Supporting carers in their own right"	Journal of Dementia Care	The role of the Admiral Nurse	Writes of role: • Focus of the nursing intervention was based on the needs of the carer, which usually has direct benefits for the patient also • The Admiral nurse project sought to redress the balance • work with each carer is open-ended and tailored individually • Developing a long term relationship with the carer and focusing carers perceived needs • no carer should go for longer than three months without being contacted by an admiral nurse • One of the characteristics of the Admiral Nurse Service is its emphasis on carers coming to terms with a variety of bereavement issues which dementing illnesses typically present" • Need for specialist nurse because priority of other professions is inevitably the person with dementia.	Collaborative working, Provision of emotional or psychological support, Provision of information
Heath (2006) "Specialist Community Nurses for Older People at home. A report on the feasibility of the role"	Prepared for the Clore Duffield Foundation	A report on the feasibility of specialist community nurses for older people in the home	Comprehensive paper about the feasibility of specialist community nurses. Small section on what AN are and their role (p. 9). "Admiral Nurses strengthen existing primary and secondary care services for people with dementia"	Collaborative working, Promoting positive approaches, Provision of emotional or psychological support, Provision of information, Skilled assessment of needs of carer/patient
Hibberd, Lemmer et al (2008) "A family-centred approach to dementia care"	Journal of Dementia Care		Focus on family-centred approaches. Comments on a study they are currently undertaking to see whether admiral nursing can be affected by family centred approaches	Collaborative working, Promoting positive approaches

Hibberd (2011) "The Admiral Nurse Academy: A clinical academic pathway to support a specialist dementia nursing service"	Quality in Ageing and Older Adults	The role of the Admiral Nurse	Exploration of development & the academy. Writes that: • AN aim to enhance carer's feelings of well-being, value their caring role, help them retain a sense of self and provide them with opportunities to make choice about their caring role • AN role much broader than case-based work. They also act as educators and consultants to support the development of dementia care knowledge and skills in health and social care workforce • AN receive regular continuing professional development - support their clinical and academic learning • AN Practice Development Strategy in 2007 identified the need to: clarify the role and expectations of Admiral Nurses, ensure consistency in application of systematic approaches to working with carers and families and integrate evaluation into regional practice. • overarching objectives of the AN Academy are to maintain the distinctive specialism of Admiral Nursing, provide support to the admiral nurse induction programme, update and disseminate the Admiral Nurse Competency Framework and share best practice	
Keady (2005) "The role of the Psychiatric nurse"	Psychiatry	The role of the Admiral Nurse	Describes day to day practice: Work with family carers as prime focus, provide practical, emotional support, information and skills, deliver education and training, provide consultancy, promote best practice and person centred dementia care	Collaborative working, Promoting positive approaches, Provision of emotional or psychological support, Provision of information
Soliman (2003) "Admiral Nurses. A Model of family assessment and intervention"	Community Mental Health Nursing	The role of an Admiral Nurse	Writes of role: • The consultancy role includes: advice on casework, education and training and promoting high standards of care for PWD and their carers at a local or strategic level. • Benefits of intervening at early stage and playing a	Developing carers skills, Guidance about accessing services, Provision of emotional or psychological support, Provision of information

			preventative role • Forming therapeutic relationship with the person with dementia and the carer at the assessment stage underpins all future care • Important to explore problems fully and be non-judgemental • Tension in maintaining a balance between the case-work and the consultancy aspects of role	
Woods (1995) "Dementia Care: progress and prospects"	Journal of Dementia Care	The role of an Admiral Nurse	• Makes analogy with Macmillan nurses, who adopt a similar specialist support, advice, counselling and information role • Suggests it is important for the service not to become disconnected from the input of other disciplines- perhaps its scope might be broadened beyond nursing per se?	

Policy Documents = 3

Title	Written by	Page No.	What is discussed?	Brief description of content	Notes
Spotlight on Dementia Care	The Health Foundation	85-86	A project involving admiral nurses	Focus on post diagnostic support groups (PDS). Run by Admiral Nurses. "The structured programme entails six weekly sessions, each lasting two and a half hours, with a maximum of seven pairs of participants." "participants need to be able to acknowledge	Includes a breakdown of specific programme run by the Manchester Health and Social Care Trust
Specialist Nurses (2010)	Royal College of Nursing	8		Document produced which explains several different Specialist nurses and explains job role. Admiral Nurse included.	Very basic overview of what Admiral Nurses do. Includes a quote from a carer
From values to action: The Chief Nursing Officer's review of mental health nursing	Department of Health	28	The role of Admiral Nurses	"Family carers are the prime focus of their intervention". "Provide practical advice, emotional support, information and skills". "Actively seek formal feedback from the carers with whom they work".	Provides a "good practice" example

Appendix 5: Table of included systematic reviews

Author and year	Review aim and type of review	Number of included studies, Sample size (N) and Broad categories of Interventions	Outcome measures	Overall findings	Key limitations & notes
Brodaty (2003)	Aim: To review published reports of interventions for caregivers of persons with dementia, excluding respite care. Type: Meta-analysis	**Number of included studies**: 30 studies. Randomised or quasi-experimental trials **Sample**: 2040 care givers. Range of 16-206. Median is 53. **Interventions**: 34 different psychosocial interventions looked at. No specific examples given.	Primary outcome measures: psychological morbidity and burden	Effect sizes: **CG psychological morbidity**: 0.31, 95% CI, 0.13 to 0.50 **CG Burden**: 0.09, 95% CI, -0.09 to 0.26 **Changes in patient mood**: 0.68, 95% CI, 0.30 to 1.06 **CG knowledge**: 0.51, 95% CI, 0.05 to 0.98 **Overall effect**: 0.32, 95% CI, 0.15 to 0.48 7 studies measured time until nursing home placement, 2 showed significant effect sizes. Caregiver interventions have a modest but significant effect on knowledge, psychological morbidity, coping skills and social support. Caregivers were satisfied with interventions, felt coping skills and relationship with the patient had improved, and they would use training again. Less successful treatments were short educational programmes that did not enhance knowledge, support groups alone, single interviews, brief interventions or courses that were not supplemented with long term contact.	The findings regarding the predictors of positive ES's are based on a small number and should be interpreted with caution – the heterogeneity of sample characteristics and study design contribute to a considerable amount of variance but cannot be controlled due to lack of information and small number of studies. The numbers of subjects in trials were small, they had limited power theretofore statistical comparisons were multiple and intention-to-treat analysis were largely not performed.
Cooke et al (2001)	Aim: To identify the types of components that have been utilised in psychosocial /psychoeducational interventions	**Number of included studies**: 40 **Sample**: Sample sizes ranged from n-5 to 5,307 caregivers. Predominantly female.	Five outcome categories were selected: Knowledge Psychological well-being Caregiver burden	**Psychological well-being**: 41% of the 29 studies reported improvements. *Social components:* 21 of these studies used a social component within the intervention. There were in total 25 interventions assessed within the 21 studies & 60% of these showed improvements on psychological wellbeing. *Cognitive components:* 17 studies used a cognitive	Issues with baseline figures. Some studies had high levels of depressed patients at baseline. One study did not record any baseline figures at all. Measures of burden, especially Zarit's Burden Inventory appear to be

	for dementia care givers, and to evaluate the success of the different components or combination of components in producing positive outcomes for dementia caregivers. Type: Systematic review	**Interventions**: The review focused on psychosocial and psychoeducational interventions. The classification of intervention components found 15 interventions: General education General discussion Support group Social Skills training Social support Social activities Cognitive problem solving Cognitive therapy Cognitive skills Practical care-giving skills Record keeping Relaxation Behaviour therapy Psychotherapy and Counselling Respite Misc.	Social outcomes General	component. There were 19 interventions tested, of these 42% demonstrated improvements. **Caregiver burden**: 30% of the 22 studies found a reported improved level of burden. *Social components*: 15 of the studies assessing caregiver burden used a social component as part of the intervention. There were in total 19 interventions assessed within the 15 studies & 47% of these showed improvements on caregiver burden. *Cognitive components:* 10 studies used a cognitive component. Within the 10 studies 12 interventions were evaluated. 42% demonstrated improved levels of caregiver burden. **Social outcomes**: 22% of the 13 studies reported improvements. *Social components*: 8 studies assessed social outcomes and included social components. There were in total 14 interventions evaluated within the 8 studies & only 36% of those resulted in improvements on social outcomes. *Cognitive components:* 6 studies used a cognitive component. Within the 6 studies, 8 interventions were evaluated. None of these interventions showed any improvement. Despite the low levels of improvement demonstrated, participants in the interventions have "rarely exhibited any deterioration" in the outcomes. **Knowledge:** 69% of the 16 studies showed improvements. However, of the 11 studies which showed improvement, only 3 (27%) also showed improvements on psychological wellbeing and burden.	"insensitive to change". Many of the studies used sample sizes too small to achieve statistical power.
Hall & Skelton (2012)	Aim: To identify the evidence and current role of occupational therapists in	**Number of included studies**: 17 studies. 5 RCT's 2 Qualitative 1 Audit	Outcome measures identified from studies. Over 30 found.	Lack of robust literature on interventions delivered by occupational therapists, and in fact also other health care professionals. Only three studies that showed a robust difference in carer	Lack of consistency of keywords used in different databases. No grey literature search and no external academics contacted. Difficult to compare the different

	supporting caregivers of people with dementia in the community. <u>Type:</u> Systematic review	4 Cohort studies. 5 systematic reviews. **Sample**: Caregivers. Total numbers not given. **Interventions**: Explored via professional group. Occupational therapists (2- a stress management programme & a wellbeing group) Multidisciplinary teams (exploring overall team input, e.g. mental health not specific interventions) Nurses (2. One the benefits of psychosocial intervention training for CPN's, the other was Woods 2003) Other health and social care professional (impact of interventions provided by a psychiatrist, clinical psychologist, speech and language therapist. All RCT's.) Non-health and social	Carer: burden, stress, strain, knowledge, health and mood. Person with dementia: severity, mood, behaviour, interaction, quality of life and rate of institutionalisation.	outcomes. Two featured interventions that had multiple components and aspects of stress management.	studies accurately due to the wide range of interventions. Levels of evidence determined by one author only. Limited to UK searches only so other information from other countries may be lost.

		care professionals (music lecturer & reminiscence specialist)			
Parker et al (2008)	Aim: To assess the effectiveness of interventions that assist caregivers to provide support for people living with dementia in the community. Type: Systematic review	**Number of included studies**: 40 studies. Meta-analyses (3) Systematic reviews (3) RCT's (34) **Sample**: Caregivers. Total numbers not given. **Interventions**: Four categories of intervention included: 1. Psycho-educational (13) 2. Support (7) 3. Multicomponent (12) 4. Other (2)	Depression, health, subjective well-being, self-efficacy and burden.	**Psycho-educational**: No significant impact found on outcome measures of burden, self-efficacy or health. Small significant scores for depression (ES= -1.93, 95% CI, -3.79 to -0.07, p=0.04) and subjective wellbeing (ES= -0.16, 95% CI, -.032 to -0.00). Meta-analysis performed on 8 of the studies. **Support**: only 2 studies showed significant results and were suitable for meta-analysis (ES= -0.41, 95% CI, -0.80 to -0.02). Small but significant on caregiver burden. **Multicomponent**: 10 had significant outcomes. (inc. self-efficacy, depression, subjective wellbeing and burden) **Other**: included exercise or nutrition (improvements in psychological distress and health benefits). CM and computer aided support showed mixed results. CBT study showed a reduction in anxiety and improvements in patient behaviour.	Self-efficacy is not an appropriate outcome measure because there is no consistent method of measurement. Limited inclusion of caregiver health measures and lack of quality of life measurements.
Peacock & Forbes (2003)	Aim: To gather and synthesis information on interventions designed to enhance the well-being of caregivers of people with dementia Type: Systematic review	**Number of included studies**: 36 RCTs. 11 rated as strong, 11 as medium, 13 as weak, 1 as poor. Only 11 strong studies analysed. **Sample**: Caregivers. Country: USA- 9 UK- 1 Australia- 1 Finland- 1	Measured outcomes: Institutionalisation of care recipient (6) Death of recipient (3) Perceived behaviour disturbances in recipient (3) Caregiver depression (3) Caregiver strain (2) Caregiver stress (2) Use of formal services (2)	Only descriptive analysis undertaken. **Case management**: The four studies have conflicting findings. Eloneimi-Sulkava et al (2001) found that it decreased the rate of institutionalisation, whereas Miller, Newcomer and Fox (1999) found it did not reduce the rate. **Education**: insufficient to improve overall caregiver psychological well-being (e.g. decreasing strain and depression). However, Brodaty et al (1997) showed institutionalization and death were reduced. **Psychotherapy**: two studies using same data but different outcomes. Consisted of 6 individual counselling sessions that focused on communication and problem solving. They were	7/11 studies did not report pre-testing tools. Authors did not always describe how the randomisation was achieved, however all 11 studies did use randomisation. All studies used convenience sampling with caregivers who had already accessed the formal system. Limits generalizability. Limited by articles retrieved. Articles which were not published were not

		Interventions: Only 11 strong studies categorised into type of intervention. Education (4) Case Management (4) Psychotherapy (2) Computer Networking (1)		required to join a support group. Did delay rates of institutionalisation. **Computer Networking**: caregivers received information, decision making support, communication and an opportunity to ask questions. No significant differences except increased confidence in decision making skills.	retrieved. No other authors who were contacted shared information on upcoming projects. Publication bias.
Pimougu et et al (2010)	Aim: Analyse the efficacy of case management programmes on health care cost, institutionalisatio n and hospitalisation. Type: Systematic review.	**Number of included studies**: 12 RCTs (6 assessed as high quality). **Intervention**: case management. Interventions undertaken in variety of settings: Interventions performed by: • Nurse (6) • Social worker (5) • Counsellor (1)	Papers included had to test one of these outcome measures: Informal costs Cost analysis Cost benefit Cost utility Cost-effectiveness Patient hospitalisation Patient emergency rates Rate of patient institutionalisation.	**Case management**: either carer or patient was prioritized – not both. Case managers were either a nurse or a social worker (iIn 9 studies the CM worked within a team). **Economic evaluation**: only 3 CM programmes provided cost analysis. After three years, the savings made by the nurse (vs the social worker) did not compensate the amount it cost to run the programme (despite lower monthly costing) **Institutionalisation**: overall CM can be effective in reducing long term care emissions which would dramatically reduce expense. Other studies found insignificant findings. **Hospitalisation**: No evidence found for positive impact of CM.	Limitations of review: Variable study quality Lack of power Short follow-up
Pinquart & Sorense n (2006)	Aim: To extend previous meta-analysis by including 127 studies with dementia carers. Type: Meta-analysis	**Number of included studies**: 127 studies No final number listed. 10 excluded due to insufficient information, 41 because they did not include a no treatment group. Which studies these are aren't listed. **Sample**: Caregivers.	Outcomes measured: Burden (using Zarit Burden interview for 32 studies, 53 using other scales) Depression (using center for epidemiology studies depression scale in 23 studies, Beck's depression index for	Effect size measured in odds ratios. **CBT:** Carer depression:0.70. 95% CI, -1.10 to -0.30 Carer burden: 0.36, 95% CI, -0.73 to -0.01 **Educational:** Carer depression: -0.27, 95% CI, -0.41 to -0.13 Carer burden: -0.15, 95% CI, -0.25 to -0.04	No limitations discussed.

		Participant numbers ranging from 4-4151 (median=23). Mean age: 63.4. 2/3rds of caregivers female. Control groups: 4-3944. Mean age: 77.6 Country: Not stated **Interventions**: Compares forms of interventions that have been evaluated in 5 or more controlled studies. • Psychoeducational interventions • CBT • Counselling/ case management • General support • Respite • Training of the care receiver • Multicomponent • Miscellaneous No of sessions: Range: 1-180 Median= 23	17 studies and other measures in 22 studies) SWB (measured using perceived quality of life scales in 8 studies, life satisfaction scales in 4 studies and 14 other scales) Ability/knowledge (assessed using questionnaires on coping abilities in 16 studies, caregivers efficacy in 14 and finally knowledge about dementia and available services in 11 studies.) Symptoms of care receiver (assessed using measures of behaviour problems in 11 studies, cognitive deficits in 8, negative affect in 4 studies and deficits in functional abilities in 5 studies) Institutionalisation (measures by the percentage of members of the experimental group and control group	Carer knowledge: 0.46, 95% CI, 0.28 to 0.64, p<0.001 Psychoeducational had significant effects on all outcomes except institutionalisation. More active roles of the caregivers had a significant effect on burden, depression, SWB and symptoms of the CR compared to information only. **Multicomponent**: Carer Depression: -0.10, 95% CI, -0.26 to 0.06 Carer Burden: -0.3, 95% CI, -0.11 to 0.05 Subjective wellbeing: -0.13, 95% CI, -0.68 to 0.41 Carer knowledge: 0.55, 95% CI, -0.55 to 1.55 Only multicomponent interventions reduced the risk of institutionalisation. (Only when structured interventions used vs non-structured). **Psychotherapy**: Carer Burden: -0.50, 95% CI, -0.86 to -0.14 **Respite**: Carer Burden: -0.26, 95% CI, -0.39 to -0.12 Carer Depression: -0.12, 95% CI, -0.24 to -0.00 Subjective wellbeing: 0.27, 95% CI, 0.03 to 0.51 CBT: effect on depression (large) and burden (small). Respite had significant but small on burden, depression and SWB.	

			placed in a nursing home)		
Pusey & Richards (2001)	Aim: To assess the evidence of effectiveness for psychosocial interventions with carers of people with dementia. Type: Systematic review.	**Number of included studies**: 30 RCT's. **Sample**: Informal carers. Total numbers not given. Country: USA- 16 UK- 8 Canada- 4 Australia- 2 **Interventions**: Psychosocial interventions (e.g. interpersonal interventions concerned with the provision of information, education, emotional support together with individual psychological interventions) Ranked as Group, Individual, Service and Technology	Outcomes: Psychological health, physical health, quality of life (including perception of burden	Technology based interventions: 2 studies (computer, telephone).Significant improvements in confidence and decision making. Positive outcomes but no specific findings on impact mental health of carers. At the time of the study, there was no evidence to support the use of psychosocial interventions that utilize technology. Group based interventions: 14 studies. Fairly weak evidence of effectiveness. Some report successful interventions but have methodological weaknesses. There was also weaknesses in the studies that reported no impact on outcomes. So there is no strong evidence of ineffectiveness either. Individually based interventions: 9 studies. No strong evidence due to methodological weakness. Service Configuration: 5 studies looking at a specific mode of service configuration (compared to conventional care or no support). Lacked random allocation Overall: the psychosocial interventions which offered the best evidence of efficacy were those that followed closely (although not completely) the Baguley & Baguley (1999) model which is developed for people with severe mental illness. It is based on three elements: the concept of expressed emotion, the stress-vulnerability model and cognitive behavioural approaches.	Limitations: Small studies Methodological weaknesses of included studies Lack of long term follow up
Schoen makers (2010)	Aim: A quantitative analysis of the effect of the different types of professional dementia home care	**Number of included studies**: 26 studies. Quasi-experimental & RCT's. **Sample**: Patients and caregivers.	Primary outcome measures: burden and depression.	**Psychosocial**: Carer depression: 0.03, 95% CI, -0.42 to 0.35. Modest but non-significant effect Carer burden: 2.94, 95% CI, -6.28 to 0.40. Showed that burden decreased in the intervention arm in a non-significant way.	Limitations: Lack of clear control Use of inappropriate outcome measures Efficacy of interventions based on population- difficult to recruit.

	interventions. Type: Systematic review	Country: Review performed in Belgium **Interventions**: Professional home care interventions VS usual care Psychosocial interventions (15 studies) Telephone/internet based (2) Case management (2) Respite care (2) Physical exercise and communication training (1)		**Respite care:** Carer burden: 0.30, 95% CI, 0.12 to 0.48. Significantly increased caregiver burden. **Telephone support**: Carer depression: 0.07, 95% CI, -2.62 to 2.75 **Case management**: Carer depression: -0.34, 95% CI, -0.73 to 0.09. Non-significant decrease in depression. Heterogeneity tests: p=0.003 (burden) & 0.007 (depression).	
Smits et al (2007)	Aim: review the evidence for the effects of combined intervention programmes for both the informal caregiver and the person with dementia. Type: Systematic review. 8 studies rated highly.	**Number of included studies**: 25 studies relating to 22 programmes. **Sample**: Dementia patients and carers in 18 of the programmes. Ranges from 15 – 4130. Country: Review performed in the Netherlands **Interventions**: Combined intervention programmes for the carer and the person with dementia.	Mental health (covered by 14 studies) Burden (13 studies) Competence (7 studies)	15 different aspects of the caregiver mental health distinguished. Three outcome categories classified: **Mental Health** (14 studies): Seven studies focusing specifically on depressive symptoms. Two showed significant improvement. Heterogeneous results were described in three. One study showed no significant effects. One study showed increased depression after intervention. Four studies focused on general mental health. Three found significant improvements and one found no significant effects. **Burden** (13 studies): Seven studies explored subjective burden. One showed a positive effect, whereas three showed no significant effect. One study demonstrated subjective burden had increased after 24 months.	Limited number of varying quality of available studies. Few number of studies that use the same measurement tools.

				The studies exploring a variety of other burden related outcomes were too small in number to be able to draw effective conclusions. **Competence** (7 studies): Competence programmes may be useful for women and ethnic minorities.	
Somme et al (2012)	Aim: to explore the impact of case management programs on clinical outcomes and the utilisation of resources by the person with dementia. Type: Systematic review	**Number of included studies**: 6 RCT's. **Sample**: Patients with dementia. Country: USA- 5 Sweden- 1 **Interventions**: Impacts of case management in patients with dementia.	Outcome measures used varied from each study.	Case management intensity was evaluated by case manager workload (the greater the case load, the lower the intensity). Used Pacala scale which used 18 pre-defined functions to assess case intensity. RCT1. Disease management. 50 case loads per manager. Based on the networking of various facilities in one city (San Diego).Small effect sizes (0.54). Patient quality of life were significantly positive but the effect size was weak (0.16) RCT2. Collaborative care. Fewer than 40 case loads per manager. Had a statistically significant impact of primary end point (intensity of behavioural problems). Caregiver stress significantly lower at 18 month follow up. Modestly significant impact (effect size: 0.24), caregiver stress significantly lower (effect size: 0.17) RCT3. Two versions were tested- 40 per person and 100 per person caseload. Statistically significant improvement in patients access to services (effect size: 0.34). Weak statistically significant effect on caregiver burden (0.04) and depression (0.03). RCT4. Focused on empowerment of the person or family through the actions of the care consultant. The positive effects were protection against the onset of depressive symptoms in caregivers (weak effect: 0.18), less use of direct community services (0.00), less information and support services other than those provided by the local branch of Alzheimer's Association (0.04).	Non-transferable to other populations. Limited data in published papers on components of integration other than case management (such as funding, organisational or managerial dimensions). Case management setting varied between each RCT.

				RCT5. Caseload of less than 50. Delayed institutionalisation at 1 year (effect size: 0.33), but that effect as lost at the 2 year check-up. RCT6. Intensive social work after an assessment at a memory clinic. 65 cases per manager. No significant impact on utilization of health or social service resources by the patient.	
Tam-Tham et al (2012)	Aim: evaluate the effectiveness of dementia case management compared with usual care on reducing long term care placement, hospitalisation and emergency department visits for adult patients with dementia. Type: Systematic review and meta-analysis	**Number of included studies**: 17 studies. All RCT's **Sample**: Caregivers Country: USA- 10 Australia- 2 Canada- 2 Finland- 2 Italy- 1 Netherlands- 1 UK- 1 **Interventions**: Looking for the effectiveness of case management in reducing source utilization (long-term case, emergency services, hospitalization)	Long term care placement as primary outcome measure. Secondary measures were: hospitalization, emergency department visits, time to hospitalization and placement in LTC facility.	Risk Ratio used as the common measure of effect. With a random-effects model used on 16 trials, there was no statistically significant effect on dementia case management compared to usual care on the risk of LTC placement (pooled RR 0.94, 95% CI [0.85, 1.03], p=0.203) Stratified analysis by follow up duration showed a statistically significant reduction in the risk of LTC placement for dementia case management compared to usual care when follow up duration was less than 18 months (pooled RR 0.61 [95% CI, 0.41, 0.91] p= 0.015). The effect deceased and was no longer significant when the follow up was at 18 months (RR 0.95 [95% CI, 0.62, 1.46] p=0.827) or greater than 18 months (pooled RR 1.01 [0.95 CI, 0.97, 1.06] p=0.654) Produced a short positive effect on long term care placement. However not statistically significant.	Did not allow for the assessment of effect of longer follow up durations on the odds of institutionalisation. Substantial variability in CM interventions. Timely and appropriate LTC placements may be considered a goal of case management in some cases but not others. Therefore they may speed up the placement into LTC. Not able to perform a stratified analysis of time to LTC placement because of limited studies using this outcome. Majority of trials lacked blinding and allocation concealment.
Thomps on et al (2007)	Aim: To examine whether information and support interventions	**Number of included studies**: 44 studies. All RCT's **Sample**: Not given.	Technology based: information, perceived social support, support satisfaction,	**Technology based interventions**: effect estimates on outcome of depression for three trials using computer was non-significant (0.62, 95% CI, -1.98 to 3.22) **Group based interventions**: 5 studies used in meta-analysis	Issues with heterogeneity of outcomes and associated measures used in each trial.

	improve the quality of life of people caring for someone with dementia. Type: Systematic review and meta-analysis.	**Interventions**: Technology based interventions (4) Individual interventions (27) Group interventions (13)	depression Group: Caregiver depression, burden Individual: Depression, self-efficacy	testing Psychoeducational for carer depression was statistically significant (-0.71, 95% CI, -0.95 to -0.46). Psychoeducational testing for burden (-2.15, 95% CI, -5.97 to 1.66). **Individual based interventions**: psychoeducational for depression (effect size: -0.21, 95% CI, -0.61 to 0.20) Self-efficacy (effect size 0.37. 95% CI, 0.28 to 1.02) but neither were statistically significant. Only group interventions (which are underpinned by psychoeducational foundations) positively impact on depression in caregivers. (Interpret with care.)	

Appendix 6: Results of the thematic analysis

Theme 1: Relational Support		
Sub themes	Supporting Evidence	Source
Carer-centred approach		
	"Put at ease quickly and made to feel important and that I wasn't in the wrong for my feelings of rejection and despair." "Love the way the Admiral Nurse always emphasised that I was her patient, not my wife." "While the Admiral Nurse understands about my mother, I am her main concern." "I am told that the Admiral Nurse is for me. The community nurse looks after the needs of the patient."	Clare et al (2005)
	Admiral nurses help the carer retain a sense of self and not become overwhelmed by the carer role. Enhancing general feelings of well-being. For example stress reduction. "Admiral Nurse entered my world." Admiral Nurses indirectly supporting the patient with dementia by helping the carer. Psychological help. The experience of being a carer being put into context of carers life. Empowerment of the carer.	Hibberd, P. (2011).
	"The CPN is for mum, the Admiral Nurse is for me."	Woods, B. and Algar, K. (2009).
Individually tailored		
	"I was confused about Mother and the Admiral Nurse did not push me, told me only what I needed to know."	Clare et al (2005)

	Provision of grief counselling if necessary. Flexibility with each carer so the programmes are tailored to what they need.	Hibberd PhD. Also found in Keady, J., S. Ashcroft-Simpson, et al. (2007).
	Avoid carer developing a dependency on an admiral nurse, instead encouraging the development of a support network.	Meredith, H. (1998).
	Helps deal with bereavement issues.	Soliman, A. (2003).
Admiral nurse as 'friend'		
	"She is the most understanding person I have ever met in my caring years and feel at ease on seeing her." "I feel like they are my close friends." "He was an absolute angel." "Could not wish for a better person to call, she is a friend as well as a nurse." "Like seeing a light at the end of a dark tunnel." "Life-saving." "They have done more for me than anyone else." "Has been my anchor and friend in my times of despair." "Made a difficult situation tolerable." "Wonderful nurse, very focused, very kind." "Our Admiral Nurse is like a friend with special expertise. Don't feel so alone." "Someone is taking notice. I am not alone in caring for my wife." "Friendly and informative, not patronising."	Clare et al (2005)

	"Angel on earth."	Kendall-Raynor, P. (2009).
	"Needs to be a friend." "Formation of this relationship is integral to making the service valued." The Admiral Nurse goes "the extra mile." Impartial and reassuring.	Hibberd, P. (2011). PhD.
	"Makes suggestions quietly without being pushy." "Nothing is too small or too difficult." Calm attitude. "Excellent personality." Admiral Nurses are seen as great a listener, which is highly valued by the carers.	Maio, L. (2011)
	Admiral nurses are non-judgemental.	Soliman, A. (2003).
	"Worth her weight in gold." "Without her I'd be depressed." "There should be more of them."	Woods, B. and Algar, K. (2009).
On-going support		
	Education about financial situations, including access to benefits. Teaching about responses to specific social situations. E.g. public toilets.	Armstrong, M. (2001).
	Support throughout the care home transition.	Burton, J. and K. W.

	Helps in the understanding of diagnosis and the impacts.	Hope (2005).
	"There have been times I would not have been able to cope without my Admiral Nurse." "Service helped when I felt most emotionally vulnerable and I felt totally supported and understood."	Clare, L. & Willis, W. (2005)
	Provision of long term support throughout the dementia journey.	Greenwood, M. and K. Walsh (1995).
	Admiral nurses praised for continuity	Hibberd, P (2011)
	Helps guide you through the "minefield ahead".	Meredith, H. (1998).
	Helps the carer in the acceptance of the new role.	Quinn, C., Clare, L., McGuinness, T., & Woods, R. T. (2012).
Theme 2: Co-ordinating & personalising support		
Facilitation(includes skills development)		
	Helping carer deal with sudden behaviour changes in person with dementia. Knowledge about new roles expectations and demands makes transition easier.	Burton, J. and K. W. Hope (2005). Sarna, R. and R. Thompson (2008).
	"Made me understand that my guilt thoughts were reasonable." "Admiral Nurse gave me coping strategies to help me through and guided me all the way." "The practical advice given had an immediate effect on our relationship with dad." "Support from the Admiral Nurse helps us think through the issues about planning support and care." "Admiral Nurse spent much time explaining- felt I was coming out of thick fog. Very grateful. Could ask questions and	Clare et al (2005)

	explain feelings. Things are much easier now I know why mother behaves in a certain ways." "My wife masks her feelings but the Admiral Nurse sees through much of it." "Helped me come to terms with it."	
	Enabling moving forward by the development of an action plan. Building on previous coping mechanism used in the relationship. Stabilisation of relationships. Facilitation of support groups and help. Negotiation with carers and people with dementia. Gives information on which services are available and where to find the appropriate information. Admiral Nurse's nursing skill and knowledge are valued by carers.	Hibberd PhD. Also found in Keady, J., S. Ashcroft-Simpson, et al. (2007).
	Normalisation of symptoms to reduce distress and concern. Encourages the carer to develop an insight into the experience for the person with dementia. Helps carer respond more appropriately. Understanding differences of opinion in care delivery. Admiral Nurses have a vast amount of dementia knowledge generally and can offer advice about situation specific problems.	Quinn, C., Clare, L., McGuinness, T., & Woods, R. T. (2012).
	Helps with form filling. Made a number of suggestions as to how to meet my wife's social needs.	Maio, L. (2011)
	"Allows me to become better equipped to deal with the problems ahead."	Sarna, R. and R. Thompson (2008).

	Knowledge about local support groups.	Weatherhead, I. (2008).
Collaboration		
	Organisation of respite. With other professional teams. E.g. Memory clinics and social services.	Burton, J. and K. W. Hope (2005).
	"The mental health team arranged contact" with the Admiral Nurse service. "If she organises any aids they are delivered the next day." "Helped get a day hospital place to stimulate her." "She makes sure she liaises with all the agencies concerned with mums care." "Mother was suspicious of any authority but the Admiral Nurse's patience and support was really good for her." "Care manager doesn't seem to communicate with Admiral Nurse." "Can be tension when GP/ specialist doesn't work with Admiral Nurse."	Clare et al (2005)
	Strong links with allied services.	Greenwood, M. and K. Walsh (1995).
	Admiral nurse acts as a go between with other professional services for the carer.	Maio, L. (2011)
	Two referral routes dependent on county.	Pinto-Banerji, L. (2002).
Advocacy		
	"Admiral Nurse not au fait with legal matters, but perhaps this is expecting too much." "System is a minefield, trying to get entitlements from the state. Admiral Nurses do a great job, but someone is needed early in the onset of the disease to tackle form-filling etc and make sure carer receives what they are entitled to."	Clare et al (2005)
	Acts as a go between with professionals when necessary, "classifying issues I did not comprehend."	Maio, L. (2011)

	Raising awareness in primary care professionals.	Thompson, R. and J. Devenney (2007).
	Consultancy role including carers, care home staff and primary care professionals	Williams, A. (2012)
	Help with social services and organisation of benefits when carers have little knowledge about their entitlements. "Explains things in a way I understand."	Woods, B. and Algar, K. (2009).
Theme 3: Challenges & threats		
Demands on the service		
	Unable to refuse new cases. The role is intended to be enduring, therefore creating a strain as more carers are assigned to an Admiral Nurse. Demands on teams. Source of referral dictates initial contact and detail of information received about the carer situation. Issues with large case loads. Large number of referrals.	Burton, J. and K. W. Hope (2005).
	More Admiral Nurses are needed, "A higher staff: patient ratio would help." "Long waiting lists." "Unable to take on new clients." "Only two nurses job sharing a huge area." "overstretched" "Contacted service in June did not get to see anyone until December."	Clare et al (2005)

	"I sincerely hope this 5-6 week gap is a one-off, as I've come to rely on her advice and support." "The process is slow and could be dealt with more quickly." "Heavy caseload results in visit every 4 months." "Acknowledgement sent [from Admiral Nurse] but no contact for 10 months." Staff shortages. "I had an Admiral Nurse but no longer have one." "Disappointed she does not call regularly; feel we are crossed off her visiting list. I know she is busy, more communication needed." (Admiral Nurse)	
	Work with each carer is open-ended and not on a pre-determined time scale.	Greenwood, M. and K. Walsh (1995).
	Broader than case based work.	Hibberd, P. (2011).
	Maintaining the balance between case work and consultancy.	Soliman, A. (2003).
Providing care across the healthcare trajectory		
	Care staff arriving at home at inappropriate times. For example, arriving at 9:30am to help person with dementia get up and dressed, by which point the carer has already done it.	Armstrong, M. (2001).
	Quality issues with statutory services.	Burton, J. and K. W. Hope (2005).
	"Doctor wasn't interested." Services unable to cope with behaviour. "She's getting worse so we are withdrawing". Day centres "too loud and noisy." Respite care received was "dreadful".	Butterworth, M. (1995).
	Admiral Nurses have overstretched resources.	Clare et al (2005)

	"Trying to make contact for attention is hard." "First Admiral Nurse didn't know what I wanted and tried to advise me about finance. Second nurse didn't know how to progress with help either." Feeling under scrutiny from the Admiral Nurse. "I'm very concerned what they might say or do." "Fast turnover of personnel." (Admiral Nurses) In relation to Admiral Nurses. "Perhaps a 6 month review with carers could be initiated." "Very lonely being a carer, and worse when visits are offered that don't happen." (Admiral Nurse) "When down and depressed when I contacted Admiral Nurse Service. Still waiting and know nothing of what they do." "Wife could only be helped through me. I was doing everything physically. Can only help carer by giving practical help in the beginning, before carer's mental condition deteriorates too far."	
	Imbalance in dementia care. All focused on person with dementia.	Greenwood, M. and K. Walsh (1995).
	Admiral nurses strengthen the existing primary and secondary care services.	Heath, H. (2006)
	Communications between services and carer lacking. Difficulties in the diagnosis process. Isolated from care when person with dementia in respite. Lack of continuity with professionals. "Pushing people into care homes." Lack of honest and trustworthy relationships.	Hibberd, P. (2011). PhD.

	Services not addressing needs.	Hibberd, P., B. Lemmer, et al. (2008).
	"Admiral Nurse services are extremely patchy and need more funding".	Kendall-Raynor, P. (2009).
	Services not responding to requests. Lacking in contact after appointments. No support from GP.	Maio, L. (2011)
	"Support groups depressing".	Quinn, C., Clare, L., McGuinness, T., & Woods, R. T. (2012).
Defining the Role		
	In relation to Admiral Nurses. "Cannot see any point to this service, having to wait weeks to discuss problems. I call the mental health team, who call in days." "Never really found out what the Admiral Nurse Service was offering. Didn't make it clear. Needed practical help, but I gathered they were offering moral support. Interested to find out what they do offer." "What they [Admiral Nurses] can do is limited." "They were very earnest and did a lot of explaining about their usefulness. I'm sure they meant well, but were not any use." "I needed practical help and was offered 'tea and sympathy"	Clare et al (2005)
	Regular professional development for Admiral Nurses.	Hibberd, P. (2011).
	Taking blood pressure of both carer and person with dementia.	Woods, B. and Algar, K. (2009).
Relationship dynamics		
	Both carer and person with dementia getting older and related health issues affecting carer role.	Armstrong, M. (2001).

	Loss of support from partner.	Burton, J. and K. W. Hope (2005).
	"Needed a period of time to get used to a new person entering the home." "Felt out of my depth in a new situation with a stranger."	Clare et al (2005)
	Stages of the relationship change. Caring role taking over personhood. Emotional restriction until person with dementia dies. Pre-existing difficult relationships cause further issues when a person begins to suffer with dementia. Loss of mutual caring relationship. Loss of stability. The need for time and space away from patient with dementia. Stigma and burden of dementia. Loss and grief overwhelming before the person with dementia dies. Situation creating difficulties in family relationships. For example, choices made about care. "Friends disappear like we have the plague."	Hibberd, P. (2011). PhD.
	Loss of family values.	Hibberd, P., B. Lemmer, et al. (2008).
	Carers can become over-protective of the person with dementia. Conflicts. Poor communication and a lack of understanding from both parties.	Quinn, C., Clare, L., McGuinness, T., & Woods, R. T. (2012).

	Person with dementia becoming dependent on the carer. Roles changing causes uncertainty. Resistance to change from both the carer and the person with dementia. Resistance to help from authorities. Embarrassment about social situations. Coalitions formed between two people and a third party. This varies and is documented as being a coalition between the Admiral Nurse and patient with dementia on one occasion. Negotiating the balance in the relationship.	
	Balancing carer needs with the needs of the person with dementia.	Sarna, R. and R. Thompson (2008).