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Specialist nursing and community support for the carers of people with dementia living at home: an evidence synthesis

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What is known about this topic

- Worldwide, there are high numbers of family members caring for people with dementia. Caring for a person with dementia may have significant impacts on the health and well-being of family carers.
- There is a need to know what interventions, including those provided by specialist nurses, are most effective in supporting carers.

What this paper adds

- Specialist nursing support for carers of people with dementia is valued by family carers, but the impact of such initiatives is not clearly established and more needs to be known about at what point in the dementia trajectory the contribution of specialist nurses can make a difference.
- Evidence is still mixed about what types of interventions support family carers of people with dementia, but the strongest evidence is for multifactorial interventions.
- It is not possible to demonstrate from the review that Admiral Nursing contribution is more or less effective than other services designed to support family carers of people with dementia, but the service they offer appears consistent with what the evidence indicates carers want and appreciate.

Abstract

Specialist nurses are one way of providing support for family carers of people with dementia, but relatively little is known about what these roles achieve, or if they are more effective than roles that do not require a clinical qualification. The aim of this review was to synthesise the literature on the scope and effectiveness of specialist nurses, known as Admiral Nurses, and set this evidence in the context of other community-based initiatives to support family carers of people with dementia. We undertook a systematic review of the literature relating to the scope and effectiveness of Admiral Nurses and a review of reviews of interventions to support the family carers of people with dementia. To identify studies, we searched electronic databases, undertook lateral searches and contacted experts. Searches were undertaken in November 2012. Results are reported narratively with key themes relating to Admiral Nurses identified using thematic synthesis. We included 33 items relating to Admiral Nurses (10 classified as research) and 11 reviews evaluating community-based support for carers of people with dementia. There has been little work to evaluate specific interventions provided by Admiral Nurses, but three overarching thematic categories were identified: (i) relational support, (ii) co-ordinating and personalising support and (iii) challenges and threats to the provision of services by Admiral Nurses. There was an absence of clearly articulated goals and service delivery was subject to needs of the host organisation and the local area. The reviews of community-based support for carers of people with dementia included 155 studies but, in general, evidence that interventions reduced caregiver depression or burden was weak, although psychosocial and educational interventions may reduce depression in carers. Community support for carers of people with dementia, such as that provided by Admiral Nurses, is valued by family carers, but the impact of such initiatives is not clearly established.

Keywords: Admiral Nurse, dementia, family caregivers, nurse specialist, review

Introduction

Worldwide, there are an estimated 35.6 million people with dementia. By 2050, this number is projected to rise to over 115 million (Prince & Jackson 2009). The majority of people with dementia live in their own homes (Prince *et al.* 2013). Although the proportion of care received from families varies by country, with those in middle- and low-income countries

providing a greater proportion of care than those in high-income countries (Wimo & Prince 2010), there are high numbers of family members caring for people with dementia in all countries. Estimates in the United Kingdom range from 476,000 to 670,000 (National Audit 2007, Alzheimer's Research Trust 2010) and in the United States, almost 11 million caregivers provide 12.5 billion hours of care each year at a value of almost 144 billion dollars (Alzheimer's Association 2010). In high- and middle-income countries, about 60% of family caregivers are female and the majority are spouses or middle-aged daughters, in low-income countries, about 80% are female and have a younger profile (Brodaty & Donkin 2009). As 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 (Wimo *et al.* 2010).

Caring for a person with dementia impacts on the physical and mental health and well-being of family carers (Ory *et al.* 1999, Connell *et al.* 2001, Pinquart & Sörensen 2003, Bunn *et al.* 2012). In the UK, government policy has highlighted the need to improve the lives of family carers (HM Government 2008, DH 2009, Scottish Government 2010) and current guidance recommends that family carers of people with dementia should have access to a range of psychosocial and practical support (NICE 2006, SIGN 2006). Despite this, the provision of support for carers is often fragmented and inadequate (Georges *et al.* 2008, Robinson *et al.* 2009, Bunn *et al.* 2012). A 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. There is a need to provide greater support for people caring for a family member with dementia, but 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.

People with dementia in the United Kingdom receive health treatment and care via the National Health Service (NHS), a tax-funded and free at the point of delivery service (DH 2013). Primary healthcare is provided for everyone via NHS-funded general practice. The provision of NHS-funded secondary care services is in the main from NHS provider organisations called Trusts, but also from not-for-profit and for-profit organisations. Local Authorities provide social workers and have a responsibility to provide care assessment processes.

Social care and long-term residential care is provided by not-for-profit and for-profit organisations and publically funded only for those meeting low-income criteria. England is one of the small number of countries that has a government-led dementia strategy which emphasises early diagnosis, early interventions and support, inter-sectorial support and integrated working and support for carers (DH 2009).

Admiral Nurses are mental health nurses who specialise in supporting family carers of people with dementia in the United Kingdom. The concept was first piloted in London in 1990 (Greenwood & Walsh 1995) and the charity Dementia UK (<https://www.dementiauk.org/>) was established to provide the service. The charity works closely with statutory NHS mental health and social care services and more latterly with other types of organisations such as not-for-profit organisations and care home providers. There are currently about 100 Admiral Nurses employed in England and Wales (as of the end of 2012) working in the community and, more recently, in other settings such as primary care and care homes.

While there is a large body of work on the role of specialist nurses in the management of long-term conditions (Loveman *et al.* 2003, Cruickshank *et al.* 2008, 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). The primary aim of this review was to synthesise the literature on the scope and effectiveness of Admiral Nurses. It also addressed the question of effectiveness more broadly by situating what is currently known about the scope and effectiveness of Admiral Nurses in the context of the evidence of effectiveness of other community-based initiatives to support the family carers of people with dementia.

Design

The evidence synthesis was undertaken in two phases. Phase 1 involved a systematic review of the literature relating to the role of the Admiral Nurse and Phase 2 involved a review of community-based dementia support for family carers of people with dementia. The purpose of Phase 2 was to put the evidence about Admiral Nurses in the context of evidence of effectiveness of other community-based interventions for the family carers of people with dementia; interventions that incorporated some or all of the components of the Admiral Nurse's remit. It aimed to enable us to judge the extent to which the role provides the elements known to be effective in

community support for people with dementia and their carers. As preliminary searches identified a number of systematic reviews relating to community-based support for carers of people with dementia, Phase 2 was conducted as a review of reviews (Smith *et al.* 2011).

Literature selection criteria

Phase 1 included all types of published and unpublished literature relating to the scope and effectiveness of Admiral Nurses, including empirical research and descriptive reports. Phase 2 included systematic reviews that evaluated community-based interventions designed to support the carers of people with dementia, delivered by any type of provider. Components 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 to co-ordinate care provision. We included any outcome relating to carer physical and mental well-being, and outcomes relating to hospital admission or move into long-term care for the person with dementia. We excluded reviews that focused on residential or secondary care settings or that did not report any carer outcomes.

Search methods

Studies were identified by computerised searches of the following databases: Medline (PubMed), CINAHL, Scopus, NHS Evidence, Cochrane Library (incl. CENTRAL, CDSR, DARE, HTA), SIGLE and Google Scholar. Details of search terms can be seen in Box 1. In addition, we employed extensive lateral search techniques such as checking reference lists, performing key word searches in Google Scholar, contacting experts (e.g. Dementia UK, DeNDRoN, National Library for Health Later Life Specialist Library), and using the 'cited by' option in Google

Scholar and the 'related articles' option in PubMed. Searches were conducted in November 2012.

Data extraction and quality appraisal

Two reviewers independently screened titles and abstracts identified by the electronic search, applied the selection criteria to potentially relevant papers and extracted data using a standardised checklist. All papers were classified by study type and papers in Phase 1 were also categorised as research or non-research. Non-research items included policy publications for professionals and news reports or service announcements. We collected the following data – Phase 1: the scope and key attributes of Admiral Nurses, who they work with, outcomes and impact arising from their work and common themes; Phase 2: type of intervention and the impact on caregiver outcomes relating to physical and mental well-being.

Two reviewers independently assessed the quality of the research studies using design assessment checklists informed by several sources (Spencer *et al.* 2003, Shea *et al.* 2007, Higgins *et al.* 2011, CEBMa). The checklist for qualitative studies was an adapted version of a framework for assessing quality in qualitative research (Spencer *et al.* 2003), which has been used by the authors in previous work (Pocock *et al.* 2010, Bunn *et al.* 2012). Any discrepancies were resolved by discussion. The core quality assessment principles are summarised in Table 1.

Synthesis

In Phase 1, data are presented as a narrative and tabular summary. In addition, qualitative analysis techniques were used to draw out common themes (Marston & King 2006, Thomas & Harden 2008). All papers that provided 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 & Allen 2000, Parker *et al.* 2009), which refers to relationships between patients and practitioners, co-ordination across services, information transfer and co-ordination of care over time, and the coherent delivery of services for people with long-term conditions (Haggerty *et al.* 2003). Non-research items were used to inform sections on the scope and nature of the role but not to evaluate effectiveness. For Phase 2, interventions were classified using the

Box 1 Example search strategy: PubMed (searches undertaken on 19 November 2012)

Search 1: Admiral Nursing

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

Search 2: Admiral nursing and community support
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])

Table 1 Quality assessment criteria

Study type and tool used	Scoring criteria
Surveys CEBMa critical appraisal for surveys Scored as Yes, no or Can't answer	<ol style="list-style-type: none"> 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? 4 Was the sample representative with regard to the population to which the findings will be referred? 5 Was a satisfactory response rate achieved? 6 Are the measurements (questionnaires) likely to be valid and reliable? 7 Was the statistical significance assessed? 8 Can the results be applied to your organisation?
Controlled trial Cochrane Risk of Bias Tool Scored as Yes, No or Not clear	<ol style="list-style-type: none"> 1 <i>Sequence generation</i>, e.g. Was the allocation sequence adequately generated? 2 <i>Allocation concealment</i>, e.g. Was allocation adequately concealed? 3 <i>Blinding of participants, personnel and outcome assessors</i>, e.g. Was knowledge of the allocated intervention adequately prevented during the study? 4 <i>Incomplete outcome data</i>, e.g. Were incomplete outcome data adequately addressed? 5 <i>Selective outcome reporting</i>, e.g. Are reports of the study free of suggestion of selective outcome reporting? 6 <i>Other sources of bias</i>, e.g. Was the study apparently free of other problems that could put it at a high risk of bias?
Qualitative (adapted version of Spencer and Ritchie) Scored as 'fully', 'partly', 'not at all' or 'not clear'	<ol style="list-style-type: none"> 1 <i>Scope and purpose</i>, e.g. clearly stated research question, clear outline of theoretical framework 2 <i>Design</i>, e.g. discussion of why particular approach/method was chosen 3 <i>Sample</i>, e.g. adequate description of sample used and how the sample was identified and recruited 4 <i>Data collection</i>, e.g. systematic documentation of tools/guide/researcher role 5 <i>Analysis</i>, e.g. documentation of analytic tools/methods used, evidence of rigorous/systematic analysis 6 <i>Reliability and validity</i>, e.g. presentation of original data, interpretation/how theories developed, triangulation with other sources 7 <i>Generalisability</i>, e.g. sufficient evidence for generalisability or limits made clear by author. 8 <i>Credibility/Integrity/Plausibility</i>, e.g. provides evidence that resonates with other knowledge, results/conclusions supported by evidence. 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 findings? Has the study successfully enhanced our understanding of a new area/sample or enriched an old one?
Systematic reviews and meta-analysis AMSTAR Scored as 'yes', 'no', 'can't answer' or 'not applicable'	<ol style="list-style-type: none"> 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?

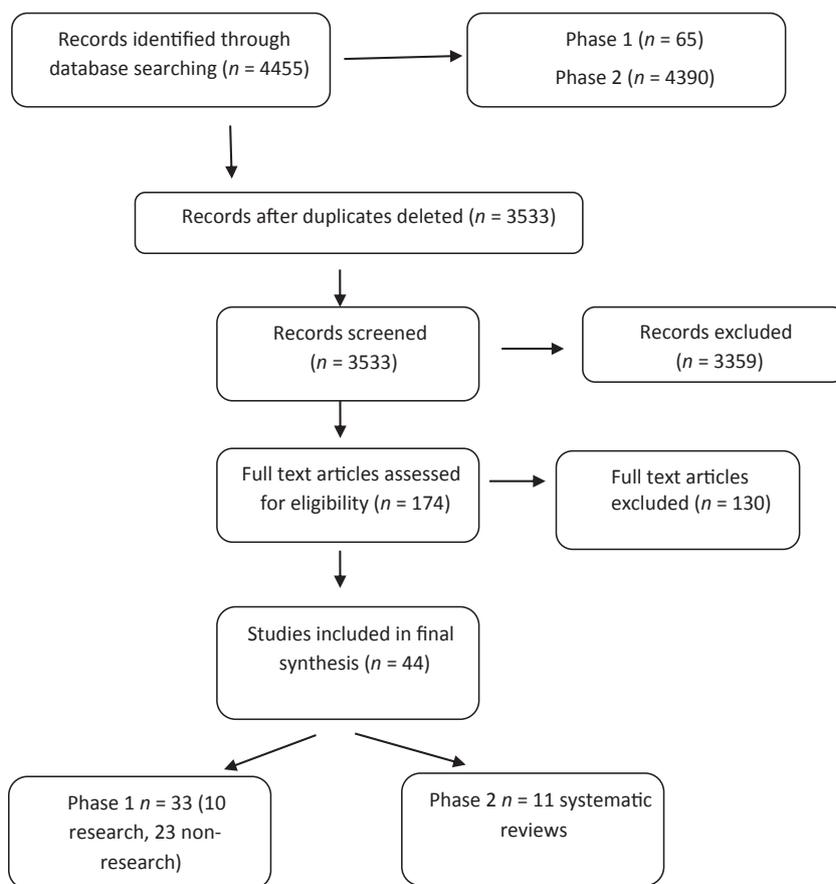


Figure 1 Identification of studies.

following categories: psychosocial support, education, case management and multicomponent interventions. Primary studies included in each review were tabulated to assess the overlap between reviews.

Description of included studies

In all, 33 items met the inclusion criteria for Phase 1 and 11 for Phase 2. An overview of the selection process can be seen in Figure 1. In Phase 1, 10 items were classified as research and the rest as non-research. Of the research items, five are published in peer-reviewed journals (Woods *et al.* 2003, Burton & Hope 2005, Dewing & Traynor 2005, Keady *et al.* 2007, Quinn *et al.* 2009), one is a published report available on the Dementia UK website (Clare *et al.* 2005), one an unpublished PhD doctorate (Hibberd 2011) and three are unpublished reports obtained from Dementia UK (Woods & Algar 2009, Maio 2011, Stamper & Taylor 2011). Non-research items were largely descriptive publications in professional journals or service announcements. Study characteristics of the research items are summarised in Table 2 and non-research items in Table 3.

We found 11 systematic reviews evaluating community-based interventions to support people with dementia and their carers; five had pooled studies in a meta-analysis (Brodaty *et al.* 1999, Pinquart & Sörensen 2003, Thompson *et al.* 2007, Parker *et al.* 2008, Schoenmakers *et al.* 2010) and the remainder presented their findings in a narrative format (Cooke *et al.* 2001, Pusey & Richards 2001, Peacock & Forbes 2003, Smits *et al.* 2007, Hall & Skelton 2012, Somme *et al.* 2012). Review characteristics are summarised in Table 4. The reviews included a total of 155 primary studies; of those, 77 were randomised controlled trials (RCTs), 52 were non-randomised studies and in the rest, it was unclear. Eighty-five studies were included in only one review, 28 in two, 16 in three, 14 in four, 6 in five, 3 in six and 1 in seven of the reviews.

Quality of the evidence

Of the qualitative studies in Phase 1, two studies scored 'high' for reliability (Keady *et al.* 2007, Quinn *et al.* 2009), two scored 'medium' (Burton & Hope 2005, Hibberd 2011) and one (Dewing & Traynor 2005) scored 'low'. However, the latter was an action

Table 2 Overview of included studies in Phase 1 Research

Study	Type of item	Focus	Participants	Method	Quality score
Burton and Hope (2005)	Published paper	Decision-making and referral management	ANs	Qualitative interviews	R – M U – M
Clare <i>et al.</i> (2005)	Unpublished report	Carers' views on the achievement of service standards	Carers	Questionnaire survey	Yes – 5 Can't tell – 3
Dewing and Traynor (2005)	Published paper	Development of competency framework	ANs	Action research	R – L U – H
Hibberd (2011)	Unpublished PhD dissertation	Exploration of the meaning of family-centred Admiral Nursing for carers	ANs (27), carers (28), PWD (6), stakeholders (18)	Mixed methods (including qualitative and questionnaires)	R – M U – H
Keady <i>et al.</i> (2007)	Published paper	Carers' experience of dementia and dialogue and shared planning with AN	AN (1), carer (1)	Autobiographical interviews	R – H U – H
Maio (2011)	Unpublished report	Carers' opinions on their contact with local AN	82 sent, 31 returned (37.5% response rate)	Carer satisfaction survey, North East Lincolnshire	Yes – 5 Can't tell – 3
Quinn <i>et al.</i> (2009)	Published paper	Explore how healthcare professionals work with carers and patients in a triadic relationship	12 people (6 female carers, 6 PWD), 3 ANs	Semi-structured interviews. Thematic analysis	R – H U – H
Stamper and Taylor (2011)	Unpublished report	Evaluation of East Kent Admiral Nursing Service (EKANS)	82 carers randomly selected (response rate not clear)	Questionnaire	
Woods <i>et al.</i> (2003)	Published paper	Evaluate outcomes for carers receiving the AN service in London/North Thames	128 carers (new referrals) to AN services	Controlled study	High risk of bias
Woods and Algar (2009)	Unpublished report	Evaluation of the Flintshire AN service	Carers (22/62 responded)	Carer satisfaction questionnaire and semi-structured interviews	Yes – 8

R, reliability; U, usefulness; AN, Admiral Nurse; PWD, people with dementia.

research project and our quality assessment framework may not have been appropriate for this type of study. The controlled evaluation (Woods *et al.* 2003) was judged to be at high risk of bias. The three mixed methods studies that involved questionnaire surveys (Clare *et al.* 2005, Woods & Algar 2009, Maio 2011) all fulfilled five of the eight categories on which they were judged. The original sample sizes in the questionnaire surveys were 62 (Woods & Algar 2009), 82 (Maio 2011) and 1607 (Clare *et al.* 2005), and the response rates were 36%, 37.5% and 33% respectively. These low response rates suggest that the findings may not be generalisable to all users of the service.

In Phase 2, no review met all of the quality criteria and five scored six or less. In addition, a number of the reviews highlighted the poor quality of included studies and problems such as small sample sizes and inadequate descriptions of interventions. Quality appraisal scores can be seen in Table 2 and 3.

Results

Phase 1: the Admiral Nurse role – scope, nature and key attributes

From the available literature, it was identified that a key part of the Admiral Nurse role involved the provision of emotional and psychosocial support to the family carers of people with dementia (Burton & Hope 2005, Clare *et al.* 2005, Hibberd 2011), which may be ongoing throughout the stages of dementia (Soliman 2003, Burton & Hope 2005, Keady *et al.* 2007). Admiral Nurses were reported to be important sources of 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 (Burton & Hope 2005, Clare *et al.* 2005, Woods & Algar 2009, Maio 2011). Although Admiral Nurses were not reported to be delivering hands-on physical or technical care, they

Table 3 Non-research items from Phase 1

Author and journal	Type of item	Brief description of content	Information regarding services provided by AN
Armstrong (2008), <i>Journal of Dementia Care</i>	Service announcement	Describes Admiral Nursing direct. Uses case studies of recent calls to the service to show how it works	Telephone support
Armstrong (2001), <i>Nursing Standard</i>	Descriptive publication in professional journal	AN team leader provides description of the role	Information Psychological and emotional support
Braker (2007), <i>Nursing Times</i>	Descriptive publication in professional journal	Describes a support group called 'Joe's Club' set up by ANs	Involved in facilitating peer support for carers
Butterworth (1995), <i>Journal of Mental Health</i>	Account of experience of a carer	Information about the role of ANs	
'Friends of the Elderly', <i>Journal of Dementia Care</i>	Service announcement	Announcement that the charity 'Friends of the elderly' has appointed an AN to work in its care homes	Working in Care Home
Ghiotti (2009), <i>Dementia</i>	Description of project involving AN	Describes Dementia End of Life Care Project (DeLcAP): Supporting families caring for people with late-stage dementia at home	
Greenwood and Walsh (1995), <i>Journal of Dementia Care</i>	Descriptive publication in professional journal	Describes key aspects of AN role	Focus on carer Development of long-term relationship Offer bereavement counselling
Heath (2006), <i>The Clore Duffield Foundation</i>	Report	Report on the feasibility of specialist community nurses for older people in the home – includes small section on ANs	
Hibberd <i>et al.</i> (2008), <i>Journal of Dementia Care</i>	Review of literature	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	Family-centred approaches
Hibberd (2011), <i>Quality in Ageing and Older Adults</i>	Descriptive publication in professional journal	Description of AN role and AN academy	Enhance carer well-being Act as educators and consultants Need to clarify role and expectation of AN role
Jackson (2008), <i>Mental Health Today</i>	Descriptive publication in professional journal	ANs working to improve access of BME groups to health and social care services	Collaboration with other health and social care professionals Dementia education
Keady (2005), <i>Psychiatry</i>	Descriptive publication in professional journal	Describes day-to-day practice of AN	Family carer main focus Provide practical, emotional support Skills training Person-centred care
Kendall-Raynor (2010), <i>Nursing Standard</i>	Service announcement	Introduced project involving ANs. Virtual academy set up by Dementia UK, Canterbury Christ Church University and Avante Partnership	
Kendall-Raynor (2009), <i>Nursing Standard</i>	Descriptive publication in professional journal	Description of AN role and caseload	

Table 3 (continued)

Author and journal	Type of item	Brief description of content	Information regarding services provided by AN
Meredith (1998), <i>Nursing Times</i>	Descriptive publication in professional journal	Information on the role of AN	Provision of information and advice Provision of long-term support Consultancy Organising peer support
Pinto-Banerji (2002), <i>Nursing Standard</i>	Descriptive publication in professional journal	AN describes how she liaises with other professionals including social services, primary care teams, voluntary organisations and local carer groups	Collaboration with other health and social care professionals
Sarna & Thompson (2008), <i>Nursing Older People</i>	Descriptive publication in professional journal	Describes 8-week carer's programme run by ANs in Central and North West London	Education and training for carers Information provision Psychosocial support Link to peer support
Soliman (2003), <i>Community Mental Health Nursing</i>	Descriptive publication in professional journal	Information on the role of AN	Consultancy Education and training Intervention at early stages Therapeutic relationship
Thompson and Devenney (2007), <i>Primary Health Care</i>	Descriptive publication in professional journal	Describes project to offer tailored education and training in dementia to staff in GP practices	Education and training to healthcare professionals
Weatherhead (2008), <i>British Journal of Neuroscience Nursing</i>	Descriptive publication in professional journal	Describes role of AN, written by AN	Education and training to healthcare professionals in primary and secondary care Education and information for carers Collaboration with care homes Introducing and supporting life story work
Weatherhead (2009), <i>Nursing Older People</i>	Descriptive publication in professional journal	Describes role of AN, written by AN	Education, advice and support for carers and people with dementia
Williams (2012), <i>Nursing & Residential Care</i>	Descriptive publication in professional journal	Describes role working in a nursing home	Training, assessment and advice for nursing home staff Acts as champion for best practice Support for relatives of residents
Woods (1995), <i>Journal of Dementia Care</i>	Literature review on dementia care	Makes analogy with Macmillan nurses Suggests is important for the service not to become disconnected from the input of other disciplines – scope might be broadened beyond nursing per se?	Specialist support, advice, counselling and information role

reportedly provided practical support, such as helping carers obtain benefits, and access services such as respite (Burton & Hope 2005) and day hospitals (Clare *et al.* 2005). There were descriptive accounts of Admiral Nurses working in a consultancy or educational role with other professionals (Thompson & Devenney 2007, Williams 2012), but there was little

evidence on how much emphasis they placed on this aspect of their role or how they balanced consultancy and case work.

An action research study (Dewing & Traynor 2005) identified eight core competencies for Admiral Nurses. This included therapeutic work, sharing information, advanced assessment and prioritisation

Table 4 Overview of included studies in Phase 2

Study	Type of item	Focus	Participants	Method	No. reviews
Brodsky (2003)	Systematic review	Psychosocial interventions	2040 caregivers. Range of 16–206. Median is 53	Meta-analysis	6/11
Cooke <i>et al.</i> (2001)	Systematic review	Psychosocial and psycho-educational interventions	Carers, <i>N</i> : 5–5307. Predominantly female	Narrative review	6/11
Hall and Skelton (2012)	Systematic review	Role of occupational therapists in community support for carers of PWD	Carers	Narrative review	7/11
Parker <i>et al.</i> (2008)	Systematic review	Interventions to assist caregivers including psycho-educational, support and multicomponent	Carers	Meta-analysis	9/11
Peacock and Forbes (2003)	Systematic review	Interventions to enhance carer well-being	Carers	Narrative review	7/11
Pinquart and Sorensen (2006)	Systematic review	Interventions to support carers of PWD including psycho-educational, CM, respite, multicomponent	Carers, <i>N</i> : 4–4151; two-thirds female	Meta-analysis	5/11
Pusey and Richards (2001)	Systematic review	Psychosocial interventions	Carers	Narrative review	8/11
Schoenmakers <i>et al.</i> (2010)	Systematic review	Evaluation of different types of home care interventions for PWD and their carers	Carers, PWD	Meta-analysis	8/11
Smits <i>et al.</i> (2007)	Systematic review	Evaluate combined intervention programmes for informal caregiver and PWD	Carers, PWD	Narrative review	6/11
Somme <i>et al.</i> (2012)	Systematic review	Impact of case management	Carers, PWD	Narrative review	5/11
Thompson <i>et al.</i> (2007)	Systematic review	Evaluate impact of information and support on QoL of carers	Carers	Meta-analysis	9/11

PWD, people with dementia. QoL, quality of life.

of workload, balancing the needs of the carer and person with dementia, preventive care and health promotion, and promoting best practice. However, although this framework is referred to in one service evaluation (Stamper & Taylor 2011), it was not clear from the existing literature to what extent these competencies were used in the day-to-day work of Admiral Nurses. Studies referred to therapeutic relationships between Admiral Nurses and carers (Dewing & Traynor 2005, Stamper & Taylor 2011), but it was unclear how this was defined or operationalised in practice. While 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, Woods & Algar 2009, Maio 2011), the impacts or outcomes that resulted from this were not quantified.

Recurrent themes in the literature

Twenty-two items provided information for the thematic analysis, from which we identified three

overarching thematic categories (see Figure 2) relating to Admiral Nurses.

Theme 1: relational support. A distinguishing characteristic of Admiral Nurses was their carer-centred approach (Burton & Hope 2005), and there was evidence that carers welcomed a service which focused on them; ‘the CPN (Community Psychiatric Nurse) is for mum, the Admiral Nurse is for me’ (Woods & Algar 2009), ‘love the way the Admiral Nurse always emphasised that I was her patient, not my wife’ (Clare *et al.* 2005). Relational support also included the delivery of individually tailored care (Keady *et al.* 2007, Hibberd 2011) with information 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). There was evidence that carers valued interacting with a professional that they knew well and descriptions of Admiral Nurses included ‘my anchor’, ‘life-saving’ (Clare *et al.* 2005) ‘an angel’ (Kendall-Raynor 2009) and ‘worth her weight in gold’ (Woods & Algar 2009).

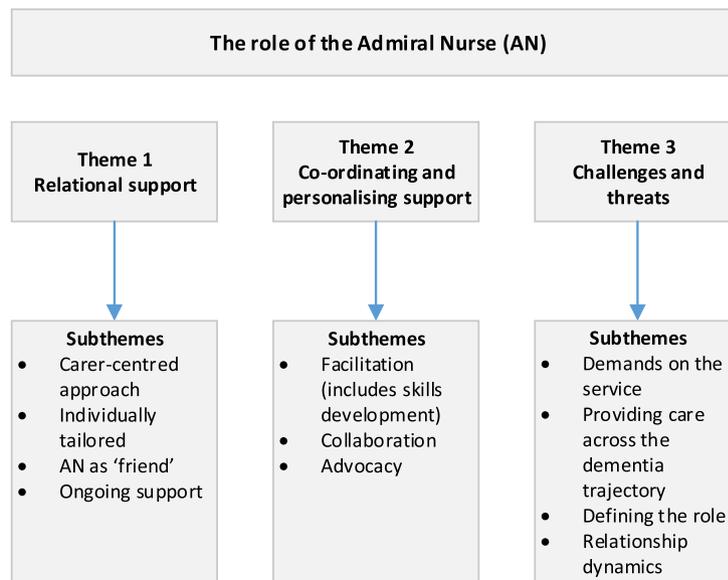


Figure 2 Themes and subthemes: this figure shows the three overarching themes and related subthemes that emerged from our analysis.

Theme 2: co-ordinating and personalising support. A commonly reported component of the Admiral Nurse role was facilitation, which included liaison with other health and social care services; 'She makes sure she liaises with all the agencies concerned with mum's care' (Clare *et al.* 2005). They were also involved in organising support (such as day hospital places and respite), providing information and advice, assisting carers to develop their own coping mechanisms (Burton & Hope 2005, Clare *et al.* 2005, Woods & Algar 2009, Hibberd 2011, Maio 2011) and acting as a consultant to other healthcare professionals (Thompson & Devenney 2007, Williams 2012). However, at times, carers felt that GPs, specialists and care managers did not work with or communicate with Admiral Nurses; 'Care manager doesn't seem to communicate with Admiral Nurse' (Clare *et al.* 2005) and that there could be confusion among Admiral Nurses and community psychiatric nurses over the boundaries of their roles (Woods & Algar 2009), potentially leading to duplication of services.

Theme 3: challenges and threats to the provision of services by Admiral Nurses. There was little evidence to say what the optimal case size or frequency of contact would be for Admiral Nurses, although there were reports that Admiral Nurses often felt unable to refuse new cases (Burton & Hope 2005) or that caseloads were sometimes too large for them to provide meaningful support to carers (Clare *et al.* 2005, Kendall-Raynor 2009, Woods & Algar 2009). In

some locations, long waits for a first appointment 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).

Carers' lack of clarity about the Admiral Nurse role was also observed; 'never really found out what the Admiral Nurse service was offering' (Clare *et al.* 2005). Admiral Nurses also had to deal with the, sometimes difficult, relationship dynamics of balancing the differing viewpoints of the carer and the person with dementia (Quinn *et al.* 2009), and deficiencies or problems with other statutory services could increase the demands on the Admiral Nurses (Burton & Hope 2005).

Admiral Nurses: outcomes and effectiveness

Carer health and well-being. Only one controlled study evaluated 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 Nurses using the General Health Questionnaire which tests for somatic symptoms, anxiety and insomnia, social dysfunction and severe depression for the carer. A total of 128 carers were recruited who were either receiving help from Admiral Nurses or other mental health services, such as CPNs and Memory clinics. There were no significant differences between the groups, although both conventional and Admiral Nurse Services were associated with lower distress

scores which suggests that carers benefited from support irrespective of the provider.

Carer satisfaction. Four studies measured carer satisfaction with the services provided by Admiral Nurses in different areas of the United Kingdom (Clare *et al.* 2005, Woods & Algar 2009, Maio 2011, Stamper & Taylor 2011). Overall responses were positive and satisfaction with the service was high. However, the findings need to be considered in the context of low overall response rates. There was evidence (Clare *et al.* 2005) that making and maintaining contact with the service initially was found to be easy in the majority of cases, but only just over half of the respondents knew who to contact outside Admiral Nurse's hours.

Phase 2: the effectiveness of community-based dementia support

In this section of the paper, we review evidence for the effectiveness of community-based interventions designed to support the family carers of people with dementia. These are interventions that incorporated some or all of the components of the Admiral Nurses remit. Results are presented by type of intervention. The main results are summarised in Table 5.

Psychosocial interventions

Psychosocial interventions included components such as support groups, social skills training, social support, cognitive therapy, behaviour therapy, and psychotherapy and counselling. Three reviews looked at the impact of psychosocial interventions on caregiver depression or psychological well-being (Brodaty *et al.* 1999, Pinquart & Sorensen 2006, Schoenmakers *et al.* 2010). One (Brodaty *et al.* 1999) reported a significant reduction in psychological morbidity in carers, but the others found no significant reduction in caregiver depression (Schoenmakers *et al.* 2010) or mental health (Pinquart & Sorensen 2006). Three reviews reported on caregiver burden (Brodaty *et al.* 1999, Cooke *et al.* 2001, Schoenmakers *et al.* 2010), but none found a significant impact; although one (Brodaty *et al.* 1999) reported further analysis which they say indicates that the involvement of both the caregiver and the person with dementia is integral to a successful psychosocial intervention. In one review, there was some evidence that psychosocial interventions led to improvements in caregivers' psychological well-being (Cooke *et al.* 2001) with the integration of a social component, such as support groups or social activities, appearing to increase effectiveness.

One review (Brodaty *et al.* 1999) found some evidence to suggest that psychosocial interventions pre-

vented or delayed the admission of people with dementia to nursing homes. Of seven studies that measured time until moving to a nursing home placement, two found a significant impact and two an insignificant, but longer median time until move to a nursing home.

Education/psycho-educational interventions

Four reviews looked at the impact of educational interventions on caregiver mental well-being (Peacock & Forbes 2003, Pinquart & Sørensen 2003, Thompson *et al.* 2007, Parker *et al.* 2008). Three (Pinquart & Sørensen 2003, Thompson *et al.* 2007, Parker *et al.* 2008) found a significant reduction in caregiver depression with one (Pinquart & Sorensen 2006) suggesting that interventions that require active participation (such as role playing) had the most positive effect and one (Thompson *et al.* 2007) finding that a group-based intervention was more effective than one which was individually administered. The other (Peacock & Forbes 2003) reviewed four studies on educational interventions but found no improvement in caregiver psychological well-being, including strain and depression.

Three reviews (Pinquart & Sørensen 2003, Thompson *et al.* 2007, Parker *et al.* 2008) reported caregiver burden but only one (Pinquart & Sorensen 2006) found a reduction. Two reviews measured the impact of education-based interventions on subjective well-being (Pinquart & Sorensen 2006, Parker *et al.* 2008) and found small but significant improvements, but the two that measured self-efficacy (Thompson *et al.* 2007, Parker *et al.* 2008) found no significant impact. There was mixed evidence on the effect of educational interventions on the number of people moving to a nursing home (Peacock & Forbes 2003, Pinquart & Sorensen 2006).

Case management interventions

Two reviews (Peacock & Forbes 2003, Schoenmakers *et al.* 2010) looked at the impact of case management on depression in carers; neither found a significant reduction although one (Schoenmakers *et al.* 2010) found a non-significant reduction in symptoms of depression in caregivers. One review (Somme *et al.* 2012) found some impact on quality of life particularly if case management was integrated into other healthcare services. There was inconclusive evidence about whether case management might delay moving the person with dementia to live in an institutional setting (Peacock & Forbes 2003, Somme *et al.* 2012).

Multicomponent interventions

Three reviews included studies which evaluated the impact of multicomponent interventions on caregiver

Table 5 Summary of main results from systematic reviews included in Phase 2 of the synthesis

Study ID	N included studies	P	Interventions	Caregiver depression/ psychological well-being	Caregiver burden	Caregiver other outcomes	Person with dementia outcomes
Brodady (2003)	30 RCTs/quasi-experimental	C	Psychosocial	<i>Psychological morbidity:</i> SMD 0.31, 95% CI, 0.13 -0.50*	SMD 0.09, 95% CI, -0.09 to 0.26	<i>Knowledge:</i> 0.51, 95% CI, 0.05-0.98*	<i>Changes in mood:</i> 0.68, 95% CI, 0.30 -1.06* Time to admission to nursing home: 2/7 showed significant effect sizes
Cooke <i>et al.</i> (2001)	40 studies	C	Psychosocial Psycho- educational	<i>Psychological well-being:</i> 44 interventions (in 29 studies) Improvements in 41%	30 interventions (in 22 studies) Improvements in 30%	<i>Social outcomes:</i> 23 interventions (13 studies) Improvements in 22% <i>Knowledge:</i> improvements in 11/ 16 studies (69%) Health: 1 study showed improvements (not clear how many measured outcome)	No impact on any outcome for PWD except 1 study which showed improvement in behaviour CBT – improvements in behaviour
Hall and Skelton (2012)	17 (5 RCTs, 2 Qual, 1 audit, 4 cohort, 5 SRs)	C	Community support	1 study showed improvement in stress (not clear how many measured this outcome)	1 study showed improvements (not clear how many measured this outcome)	<i>Psycho-educational:</i> no significant impact on health. Small improvement in subjective well-being (ES = -0.16, 95% CI, -0.032 to -0.00)*	
Parker <i>et al.</i> (2008)	40 studies (6 SR, 34 RCTs)	C	Mixed – psycho- educational (13), support (7), multicomponent (12), other (2)	<i>Psycho-educational:</i> small effect for depression (ES = -1.93, 95% CI, -3.79 to -0.07, <i>P</i> = 0.04)* <i>Multicomponent:</i> 10 had significant outcomes (including self-efficacy, depression, SWB, burden) No improvement in depression scores from <i>Education or CM</i>	<i>Psycho-educational:</i> no significant impact Support: Small reduction (ES = -0.41, 95% CI, -0.80 to -0.02)* <i>Education:</i> no improvement		<i>Admission to long- term care:</i> CM – 1 (of 4) study found decrease, 1 no difference <i>Education</i> – 1 (of 4) study found admission delayed <i>Psychotherapy:</i> 1 (of 1) study found admission delayed
Peacock and Forbes (2003)	36 RCTs (11 strong studies included in analysis)	C	Mixed – included education, case management and psychotherapy				

Table 5 (continued)

Study ID	N included studies	P	Interventions	Caregiver depression/psychological well-being	Caregiver burden	Caregiver other outcomes	Person with dementia outcomes
Pinquart and Sorensen (2006)	127 studies	C	Mixed – psychosocial, psycho-educational, case management, education, multicomponent	<p><i>Depression ES:</i> <i>CBT:</i> -0.70, 95% CI, -1.10 to -0.30*; <i>Psycho-educational:</i> -0.27, 95% CI, -0.41 to -0.13*; <i>Counselling/CM:</i> -0.20, 95% CI -0.63 to 0.23; <i>Multicomponent:</i> -0.10, 95% CI, -0.26 to 0.06; <i>Respite:</i> -0.12, 95% CI, -0.24 to -0.00* <i>SWB ES:</i> <i>CBT:</i> 0.37, 95% CI -0.27 to 1.01; <i>Psycho-educational:</i> 0.24, 95% CI 0.04-0.44*; <i>Counselling/CM:</i> 0.42, 95% CI -0.01 to 0.85; <i>Multicomponent:</i> -0.13, 95% CI -0.68 to 0.41; <i>Respite:</i> -0.27, 95% CI 0.03-0.51*</p> <p><i>Mental health:</i> <i>Technology based</i> (2 studies) no impact; <i>Group based:</i> 14 studies. Impact not clear; <i>Individually based:</i> 9 studies. No strong evidence</p>	<p><i>CBT ES:</i> -0.36, 95% CI, -0.73 to -0.01*; <i>Psycho-educational:</i> -0.15, 95% CI, -0.25 to -0.04*; <i>Counselling/CM:</i> -0.50, 95% CI -0.86 to -0.14*; <i>Multicomponent:</i> -0.3, 95% CI, -0.11 to 0.05; <i>Respite:</i> -0.26, 95% CI, -0.39 to -0.12*</p>		<p><i>Admission to long-term care OR:</i> <i>CBT:</i> 1.20 (only 1 study in analysis); <i>Psycho-educational:</i> 1.09, 95% CI 0.63-1.89; <i>Multicomponent:</i> 0.65, 95% CI 0.44 -0.98*; <i>Respite:</i> 0.76, 95% CI 0.44 -1.32</p>
Pusey and Richards (2001)	30 RCTs	C	Psychosocial interventions (categorised as Group, individual, Service and Technology)				
Schoenmakers et al. (2010)	26 studies. Quasi-experimental and RCTs	C, PWD	Mixed – psychosocial (15), telephone/Internet based (2), CM (2), respite (2), physical exercise and communication training (1)	<p><i>Depression ES:</i> <i>Psychosocial:</i> 0.03, 95% CI, -0.42 to 0.35.; <i>CM:</i> -0.34, 95% CI, -0.73 to 0.09; <i>Telephone support:</i> 0.07, 95% CI, -2.62 to 2.75</p>	<p><i>Psychosocial/ES:</i> 2.94, 95% CI, -6.28 to 0.40 non-significant decrease. <i>Respite care:</i> 0.30, 95% CI, 0.12-0.48* Significantly increased caregiver burden</p>		

Table 5 (continued)

Study ID	N included studies	P	Interventions	Caregiver depression/ psychological well-being	Caregiver burden	Caregiver other outcomes	Person with dementia outcomes
Smits <i>et al.</i> (2007)	25 studies (most not RCTs)	C, PWD	Combined intervention programmes for carer and PWD	Depression: 7 studies: 2 significant improvement, 3 mixed results, 1 no significant effect, 1 increase. General mental health: 4 studies: 3 found significant improvements, 1 no significant effects Depression: 2 studies found a weak but significant effect* Caregiver stress: 2 studies found significant effects*	7 studies: 1 positive effect, 3 no significant effect, 1 increase, 2 mixed effects		
Somme <i>et al.</i> (2012)	6 RCTs	PWD	Case management		1 study found a weak but statistically significant effect*	Carer satisfaction – weak significant improvement in 1 study*	Admission to long-term care: 1 delay at 1 year* (but effect lost at 2 years), 1 no difference Use of health and social services: 3 no significant impact, 1 reduction in use of community services, 1 improvement in access to services Intensity of behaviour problems: improved in 1 study*
Thompson <i>et al.</i> (2007)	44 RCTs	C	Information and support: technology based (4), individual (27), group (13)	Depression Technology based: WMD 0.62, 95% CI, -1.98 to 3.22; Group-based psycho-educational: -0.71, 95% CI, -0.95 to -0.46*; Individual psycho-educational -0.21, 95% CI, -0.61 to 0.20 Self-efficacy Individual psycho-educational WMD: 0.37, 95% CI 0.28–1.02	Group-based psycho-educational; WMD -2.15, 95% CI, -5.97 to 1.66; Group-based support: WMD -0.40 (-5.69 to 4.90)		

P, participants; C, carers; PWD, people with dementia; CM, case management; SWB, subjective well-being; WMD, weighted mean difference; RCT, randomised controlled trial. *Statistically significant.

depression and carer burden. One review reported no significant impact on either outcome (Pinquart & Sorensen 2006), and one (Smits *et al.* 2007) reported no significant impact on caregiver burden and mixed impact on depression. The other review (Parker *et al.* 2008) suggests that multicomponent interventions such as those provided in The New York University Study (Mittelman *et al.* 2004a,b) and the REACH studies (Burns *et al.* 2003, Eisdorfer *et al.* 2003, Gitlin *et al.* 2003, 2005), which included family counselling and weekly support groups, can have a positive impact on carer depression and burden. There was evidence from two reviews (Pinquart & Sorensen 2006, Smits *et al.* 2007) that multicomponent interventions could significantly delay or reduce admission to a nursing home, although it was suggested that interventions needed to be highly structured to be effective (Pinquart & Sorensen 2006).

Types of people delivering the interventions

Most reviews provided little information about who delivered the interventions being evaluated, so it was generally not clear whether nurses were involved. One review (Hall & Skelton 2012) evaluated the role of occupational therapists in supporting caregivers 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, comparing Admiral Nurses to community mental health teams, is reported in Phase 1 (Woods *et al.* 2003). The other was a RCT which evaluated psychosocial intervention training for community mental health nurses designed to equip nurses to help enable caregivers to cope with caring for a person with dementia (Moniz-Cook *et al.* 2008); they reported a significant improvement in levels of caregiver anxiety.

Discussion

In the discussion, we provide a summary of the main findings from the two phases of the synthesis and consider the implications for specialist nursing roles and for interventions with a focus on carer support as the mechanism that enables people with dementia to live independently at home.

Phase 1

We found 33 papers, reports or articles relating to the scope, nature and impact of Admiral Nurses, 10 of which were classified as research. 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 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 healthcare professionals was a part of the Admiral Nurse role, the priority level this was given or the manner in which the nurses balanced their consultancy against their casework roles was not clear. 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 appeared to lower distress scores in carers.

Several papers referred to the psychotherapeutic work and emotional support being offered by Admiral Nurses, but 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 appeared 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. There was also 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 had of the role and the ways in which respective roles and responsibilities were negotiated between commissioners and service providers.

Phase 2

The evidence relating to the effectiveness of community-based interventions for family carers of people with dementia enabled us to consider a wider literature and judge whether the Admiral Nurse role had characteristics in common with interventions that have been demonstrated to be effective. We found 11 previously published systematic reviews evaluating a range of community-based support. In general, the

evidence of effectiveness for most interventions was weak, although there was some evidence that psychosocial and educational interventions could reduce depression in carers. 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). 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.

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. The literature on specialist community nurses has also found that both patients and carers valued services that improved access to healthcare, 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 are further validated by the reported high levels of carer satisfaction (Clare *et al.* 2005, Woods & Algar 2009, Maio 2011). It is not possible to demonstrate from the review that Admiral Nursing contribution is more or less effective than other services designed to support family carers of people with dementia. It is however possible to argue that the type of service they can provide is consistent with the evidence as to what family carers of people with dementia want and appreciate.

Health and social care policy in the United Kingdom advocates inter-professional working and highlights the importance of better integration between health and social care (DH 2010, Goodwin *et al.* 2012) and third sector providers (House of Commons Bill 2010–11). There were descriptive accounts which suggested that Admiral Nurses collaborated with health, social care and voluntary sector providers to facilitate the provision of appropriate care for carers and their family member with dementia. Admiral Nurses may have a part to play in the co-ordination of care across boundaries, but further evidence about this is needed.

An assessment of 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 context specific and highly variable. This can mean that roles become shaped by the expectations of managers and nurses themselves, resulting in wide variations in how roles are interpreted and used (Griffiths *et al.* 2013). This is not unique to Admiral Nurses or dementia care and reflects the tension between providing context-sensitive, responsive care and providing a consistent service whose impact is measurable (Forbes *et al.* 2002, Aranda & Jones 2008, Chapman *et al.* 2009).

Dementia is a long-term condition with periods of stability but an overall course of decline in cognition often accompanied by impairments and problematic behavioural symptoms. Consequently, carers need ongoing support (Brodaty *et al.* 1999, Bunn *et al.* 2012), but who should provide this or whether it should be one professional group or service is not established. If specialist nurses such as Admiral Nurses are one way to address this need, then there are still unanswered questions, such as when is the most appropriate time to introduce the service to carers and what size of service is required to meet carers' needs. Admiral Nurses were introduced in response to service deficiency to provide services and support to compensate for the absence of other services (Burton & Hope 2005). Clearer articulation of how, when and with what effect the Admiral Nursing contribution provides carer support could help demonstrate how the service complements existing provision and provide a framework for commissioning services.

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 specialist dementia nurses. However, we found only 10 research reports or papers relating to Admiral Nurses of which only five had been published in a peer-reviewed journal. Moreover, most of the available literature is descriptive and there has been little work undertaken to evaluate outcomes for carers, to evaluate the specific interventions

they provide or to explore how they work with other health and social services.

While there is consistency in the findings about how the role is valued by carers, the extent to which the findings can be generalised beyond a specific service or individual nurses is not clear. 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 which are delivered in deteriorating conditions.

Similar issues were apparent in the review of reviews. Although 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. This may, in part, be due to methodological problems with the outcome measures used in these studies. Although depressive symptoms are one of the most widely used outcomes in caregiver intervention studies, not all carers will have depressive symptoms (Sinclair 2014). 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, there is a paucity of measures of positive capacity, self-efficacy or satisfaction for this population (Katon *et al.* 2012).

Conclusions

There is evidence that community support for carers of people with dementia (such as that provided by Admiral Nurses) is valued by family carers. The impact of such initiatives is still to be established and there is a need to define outcomes that can help organise the delivery of services to family carers of people with dementia over time. There is also a need for a shared framework that can inform how the goals of the service are defined, operationalised and evaluated. Further research should focus on identifying what specialist dementia nurses and other professionals should reasonably achieve at different stages of

the dementia trajectory and which aspects of their role are most effective.

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Author contribution

F.B., C.G. and V.D. wrote the protocol; F.B. and E.P. extracted and analysed the data; F.B. wrote the first draft of the manuscript. All authors reviewed, critically commented and edited the manuscript at each stage of its development. All authors read and approved the final manuscript.

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