

# Specialist nursing support for unpaid carers of people with dementia: a mixed-methods feasibility study

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**Disclaimer:** This report contains transcripts of interviews conducted in the course of research and contains language that may offend some readers.

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## Scientific summary

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# Scientific summary

## Background

Admiral Nursing (AN), supported by the charity Dementia UK, is the only specialist nursing service with a specific focus on supporting carers of people with dementia. The service was first piloted in Westminster in 1990 and currently provides support via more than 65 teams around the country. AN services vary in their composition, remit, funding models, case mix and other key characteristics, although all of them work to a core set of values to support carers and family members of people with dementia. All Admiral Nurses are mental health nurses who have specialised in the care of people with dementia and their carers. Admiral Nurses provide emotional support and help people to live positively with the condition, and work to join up different parts of the health and social care system so that needs can be addressed in a co-ordinated way.

A recent systematic review suggested that carers value the emotional support that AN provides, but highlighted a dearth of evidence on costs, cost-effectiveness and relationships to other health and social care services. In the absence of a secure evidence base for cost-effective interventions to support carers of people with dementia, any high-quality evaluation will provide value. However, as the Medical Research Council guidance on evaluating complex interventions advises, it is important not to rush to a full-scale, summative evaluation, such as a randomised controlled trial, before developing an understanding of the context within which interventions are delivered, their potential effects and the feasibility of full-scale formal evaluation.

## Aims and objectives

We aimed to develop this understanding by adopting a multiple-methods approach, using secondary analysis of an existing administrative data set, along with primary quantitative and qualitative data collection.

The main aims were to:

- explore the processes, individual and system-wide impacts, and the effect on outcomes and costs, of specialist support for carers of people with dementia (using the largest such service – AN – as an exemplar)
- produce guidance to inform service delivery, organisation, practice and commissioning of specialist support for such carers.

The study objectives were:

1. to carry out secondary analysis of an existing administrative database maintained by AN, to explore the relationships between the characteristics of carers and people with dementia, AN service type and input, and outcomes
2. using qualitative methods with carers, to develop and test data collection methods to inform survey development and cost-effectiveness evaluation
3. to conduct a survey of carers of people with dementia with and without AN services to explore the effect on outcomes and costs of AN services compared with usual care and to determine the feasibility of a large-scale evaluation
4. using qualitative methods, to explore the perceived system-wide impact of providing specialist support services for carers of people with dementia, as compared with usual care
5. to implement new data collection methods in AN, to facilitate future evaluative research, which could be used by other service providers
6. to build on the findings of all elements of the project and work with key stakeholders to devise best-evidence guidelines for service organisation and commissioning.

## Patient and public involvement

The views of carers played a central role in all elements of this study. The design was influenced by a year-long consultation exercise, 'Dementia, Cognition and Care', which brought together people with dementia, carers and academics to discuss and agree a research agenda. Throughout the project, we worked with Together in Dementia Everyday (TiDE), a national network of carers of people with dementia, via a dedicated virtual advisory group of carers, which fed into the project steering group. Seven carers contributed to the study via the virtual advisory group and the steering group itself had three carer members who contributed throughout.

## Methods

The project had six interlinked work packages (WPs).

### Work package 1

This WP prepared Dementia UK's AN administrative data set for research purposes and used their routinely collected data to help to understand:

- the characteristics of carers who use AN services and of the person they support
- the type and level of input carers receive from AN services
- the outcomes carers experience when using AN services.

Data sets were obtained from Dementia UK and converted into flat structures that enabled their use for research purposes. There were almost 25,000 cases and 15 data sets, covering sociodemographic information about the carer and the person with dementia, needs assessments, risk assessments, other family members, friends and agencies involved, and details of the intervention offered by Admiral Nurses. Preparing data for analysis involved structural change, creating coding frameworks and combining data sets when necessary. Most analysis was descriptive, but longitudinal data on need were analysed to explore change over three time points, using Friedman's test and the Wilcoxon signed-rank test, as post hoc tests with Bonferroni adjustment.

### Work package 2

There were two elements to this WP:

1. to establish what outcomes are important to carers in terms of their actual or anticipated use of specialist nursing support
2. to identify ways of measuring these outcomes in a robust way that would be acceptable to, and feasible for, carers, both for our survey in WP 3 and when used in service settings (WP 5).

In-depth qualitative research with 35 carers of people with dementia explored the outcomes that they felt were influenced by the quality and level of support they received, either from AN (in areas with this service) or from the alternative support available (in areas without AN). Interviews and focus groups were audio-recorded. We used the framework principles of case and theme-based analysis and data reduction through summarisation and synthesis to analyse the data and identify outcomes that were important to carers and might be influenced by carer support. We then mapped a shortlist of standardised outcome measures onto these outcomes to see which fitted best. Finally, in-depth cognitive interviews with a subsample of these carers tested these measures and the survey questionnaire. We also collected feedback from our virtual carer advisers and the steering group. Carers were asked about the feasibility of completing a questionnaire electronically and in hard copy.

### Work package 3

The questionnaire for the survey was developed and tested as part of WP 2.

We generated simple, two-stage cluster samples of local authority areas that had 'standard' AN services and broadly similar local authority areas (matched using the Department of Health and Social Care's Social Care Efficiency Tool) without AN services. AN carers were identified from current caseloads, using a sampling fraction of 1 in 6, with each service given a randomly selected starting point. Carers in areas without AN services were identified through a variety of routes, including local and national voluntary organisations, Join Dementia Research and TiDE.

The survey was developed and tested within an electronic survey system (Qualtrics, Provo, UT, USA, and Seattle, WA, USA), with a paper version available for those who preferred this mode. Data were analysed initially in IBM SPSS Statistics version 24 (IBM Corporation, Armonk, NY, USA) to describe and compare the two groups across all of the data collected, and to explore if and how the outcomes varied between them, to inform the health economics analysis.

The outcomes and cost of services data were then analysed further using Stata® (StataCorp LP, College Station, TX, USA) and adopting a number of approaches to deal with the differences between the two groups, including regression, propensity score matching and instrumental variable analysis.

### **Work package 4**

In this WP, we explored health and social care professionals' views of the system-wide impact of services designed to support carers of people with dementia, with a specific emphasis on specialist nursing support of the type provided by AN. We selected two areas with AN services and two matched areas without. Within each area, we invited key health and social care professionals in dementia care and support for carers, from both the statutory and the third sectors, to be interviewed either face to face or over the telephone. All interviews were digitally recorded and transcribed. Data from the transcripts were then summarised and organised in spreadsheets, using the Framework approach, and analysed thematically.

### **Work package 5**

Work package 5 was designed to ensure that the learning from this research informed practice and supported future evaluation. We worked with Dementia UK to inform its data collection processes, using the framework established in WP 2 as a starting point. This built on the work in prior stages to understand the feasibility for dementia service providers, and acceptability to carers, of using a range of validated outcome measures as part of routine data collection. We planned to pilot the new framework with one AN team to test its feasibility in the field.

### **Work package 6**

Work package 6 centred on a stakeholder workshop in which we presented the findings of all elements of the research, worked with stakeholders to identify the key messages arising from the research and discussed data collection at a local level to inform both service development and evaluation.

## **Results**

### **Work package 1**

Data on 24,825 cases, in 15 different data sets, were received from Dementia UK, of which 85% related to closed cases, 14% related to current cases and 1% related to cases on waiting lists. Not all data sets contained information on all cases. A total of 358 cases had needs assessment data for at least three time points and were used to examine change over time. One-third of the carers were aged > 75 years and were caring for someone aged > 75 years, and the predominant relationship between the carer and the person with dementia was spouse or partner. Over one-third of referrals to AN had come from mental health services and almost one-fifth had been self-referrals. The coding of AN activity showed five main types of intervention: assessment and monitoring; discussion, information provision and advice; care co-ordination; emotional support/counselling; and practical support. Forty per cent of carer/person with dementia dyads had been assessed as being 'at risk' at some point in their contact with the service.

Admiral Nurses worked with carers, the person with dementia and other agencies, including the police, to reduce the likelihood of harm from these risks. Positive change over time was evident in relation to several outcome domains, including medication management, insight into dementia, coping with the symptoms of dementia, informal support and time for the carer.

### Work package 2

The aim of this WP was to establish a data collection framework for the survey in WP 3. The analysis of the interview and focus group data identified three key outcome areas that are important to carers and appear to be influenced by carer support (and AN in particular). We selected three standardised instruments to measure these:

1. carer confidence, as measured by the Family Caregivers' Self-Efficacy for Managing Dementia (SEMD) scale
2. carer quality of life, as measured by the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)
3. carer mental and physical health, as measured by the EuroQol-5 Dimensions, five-level version (EQ-5D-5L).

### Work package 3

In-scope and usable questionnaires were received from 346 carers, of which 46% were from AN service users and 54% were from carers in non-AN areas. It was not possible to calculate an overall response rate for the survey because of the different ways in which carers were identified and recruited.

As a group, our survey carers were older and more intensely involved in caring than carers of people with dementia who were identified in a recent, nationally representative sample survey of all types of carers. The AN carers were older than the non-AN carers and were more likely to be the main carer, to be caring for a spouse/partner, to be caring for someone in the same household, to report financial difficulties, to provide both personal and physical care and to care for > 18 hours per day.

There were also differences between the two groups in the outcomes reported on our selected measures. These were explored in detail in the health economics analysis. This showed that, across our sample of carers, better outcomes were associated with lower health needs. Worse outcomes were associated with financial difficulties, a lack of a replacement for a break and greater reported severity of dementia symptoms.

Carers supported by AN tended to have greater needs in terms of the type and total hours of care provided. Having controlled for differences in characteristics between carers supported and those not supported by AN, the former appeared to have better outcomes, but the differences did not reach statistical significance. We found few differences in the health or social care costs incurred by carers receiving AN support and carers not so supported, or in the costs incurred by the people with dementia whom they cared for. However, we did not discount copayment for social care, which in some cases was substantial. The estimated cost of providing an AN service, per carer per year, was £709–742.

### Work package 4

Case studies in four sites with a spread of ethnic diversity and rural/urban mix were included (two sites with AN services and two sites without). Across the four areas, 58 professional stakeholders in key positions were identified, 20 of whom were eventually interviewed by telephone. It was clear from these interviews that the system-wide impact of services such as AN was not well understood and was rarely measured. Respondents suggested that such effects are particularly difficult to capture, as prevented crises cannot be observed. Nevertheless, the consensus was that these preventative services were valuable and did reduce pressure on statutory services.

A common theme across all sites was the significant financial pressure that commissioners and providers were under. Admiral Nurses were valued, but they were seen as an expensive resource. Given the challenge of reaching and providing continuity to the growing numbers of people with dementia and their carers,

one solution appeared to be a tiered model in which specialist nurses, such as Admiral Nurses, worked with and mentored less qualified support workers and escalated/de-escalated cases as and when necessary, without discharging the carers or the people they cared for. It remains to be seen whether or not the wider impact of such an approach can be demonstrated.

### **Work package 5**

We delivered training to members of one AN team in the use of our three chosen carer outcome measures (see *Work package 2*), but piloting of the routine use of these measures by the team was not completed by the end of the study. However, at a Dementia UK meeting to discuss the outcome measures to be integrated into a new national AN data collection system, ASCOT-Carer and the SEMD scale were selected as the most appropriate tools to measure carer outcomes.

### **Work package 6**

At the stakeholder workshop, the key findings were presented and feedback was gathered from a range of stakeholders on the implications of these findings and the next steps. These were fed into our discussions and conclusions.

## **Conclusions**

This multimethod project has thrown important new light on specialist nursing support for the carers of people with dementia who are most heavily involved in caring and, in most cases, are in later old age themselves. It suggests that such support may be a key element in enabling carers to continue their support to the end or very close to the end of the dementia journey.

The outcome measures we chose for the survey were seen by carers as being appropriate when we tested them cognitively, and they were completed well in the survey. They have already proven attractive to a range of dementia care service providers wishing to evaluate their own work.

We believe that our survey may be the largest independent national survey of carers of people with dementia yet carried out. Nevertheless, the work was cross-sectional, which makes it more challenging to make comparisons between outcomes for carers with and without AN support. However, the health economics work shows that, with the right statistical approach, it is possible to use a survey instrument to explore costs and outcomes. Given the underdeveloped state of knowledge about the costs and effectiveness of support for any type of carer, this is a significant step forward, and one that opens promising space for future evaluation in an area in which randomised controlled trial designs may be difficult to implement.

One of the key drivers of the costs of dementia care – both for health and social care and for individuals themselves – is admission to long-term care. Our work was targeted at carers supporting someone who was still living at home. However, all of the elements of our project suggest that specialist support to carers may enable people to remain at home for longer than would otherwise be the case. Future research to explore this possibility would potentially be of great value.

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